

00:00:06:24 – 00:00:34:17

Bernard Namok

Hi and welcome to Yarning Disability, the FPDN podcast. I'm your host Bernard Namok Junior. I'm a proud, St Paul's , Erub, and Darnley Island man from the Torres Strait. And I'm also the son of the designer of the Torres Strait Islander flag, Bernard Namok Senior and an advocate for the First Peoples Disability Network. Join me now on Yarning Disability as we showcase First Nations people living with a disability as well as their families and carers.

00:00:34:24 – 00:00:44:19

Bernard Namok

Another industry professionals.

00:00:44:19 – 00:00:53:19

Carly Wallace

Aboriginal and Torres Strait Islander people are warned that the following podcast may contain the voices and names of people who are deceased.

00:00:55:24 – 00:01:26:13

Carly Wallace

The First Peoples Disability Network and the producers of this podcast recognize the traditional custodians of the land on which this podcast is recorded. They pay respect to the Aboriginal and Torres Strait Islander elders past, present and the future leaders of tomorrow. FPDN would like to acknowledge our founding elders and their lasting legacy, Uncle Lester Bostock and Aunty Gayle Rankin and acknowledge all first peoples living with a disability.

00:01:30:06 – 00:01:43:05

Bernard Namok

So what is the First Peoples Disability Network or FPDN and what do they do? Damien Griffiths is a leading disability advocate and the CEO of the First Peoples Disability Network.

00:01:44:01 – 00:02:12:03

Damian Griffis

Knowing that around this end of the world, my people of the Willamette Valley in New South Wales, about 3 hours north of Sydney, need foster and I can cram back in this place to say, yeah. So we're a national peak organization representing First Nations people with disability and their families. We can actually trace our beginnings to a gathering of First Nations people with disability that was held in Alice Springs back in 1999.

00:02:12:18 – 00:02:35:20

Damian Griffis

And at that gathering, every jurisdiction. So every state and territory, a male and female first nation person with disability. And from that meeting there was a number of recommendations that were made, and one of those was for people to go back to the States and set up networks of mob with disability. So myself and Uncle

Lester Bostock did that back in 2000.

00:02:35:20 – 00:02:55:01

Damian Griffis

We had the first gathering of Maori disability in New South Wales and we established together the Aboriginal Disability Network of New South Wales as it was known then back in 2000. And then over time we changed to become a national organization, the First Peoples Disability Network Australia. So yeah.

00:02:55:01 – 00:02:57:24

Bernard Namok

Tell me what type of advocacy work does Fpn do?

00:02:58:17 – 00:03:21:17

Damian Griffis

Yeah, so we do a lot of different things, but it is, as you would know, we do a lot of what's called systemic advocacy. Look, that's just a fancy name really for lobbying government. We send out a lot of different government committees providing advice and trying to give voice to more with disability, particularly when they tell us their stories and we're adding community, we try and then speak up on their behalf.

00:03:21:17 – 00:03:48:22

Damian Griffis

So we do that in a lot of different ways, a lot of policy work too. And we also have a really growing area of our work which you know very well, which is about our training. So that's an area of work for the First Peoples Disability Network that is growing all the time. So that is about educating more with disability and their families about their rights so they can speak up for themselves and hopefully get the things that they want and need.

00:03:49:08 – 00:04:15:10

Damian Griffis

And we also train the service world, if you like, about how they can provide a better service to with disability as well as those things. We do a lot of what's called individual advocacy, but that's really just about trying to help out people that need help with anything really, and so people can contact us. And it could be an issue around maybe a housing issue they're having or could be anything really.

00:04:15:18 – 00:04:32:06

Damian Griffis

They want to get support to get on the disability support pension. It could be any issue really or they're having trouble with the National Disability Insurance Scheme. They can also contact us and we will try and see what we can do. So we're going to back to people sort of represent or speak on their behalf because we can.

00:04:33:07 – 00:04:55:19

Bernard Namok

Listening to stories from myself and Aunty June about the early days of FPDN and how, you know, it's been a long and a difficult road to start off. I also want to share shine a spotlight, you know, on elders that have paved the way, you know, in this disability rights movement, it also want to talk about Uncle Lester Bostock.

00:04:56:10 – 00:05:09:24

Bernard Namok

You know, his journey is quite amazing. Tell me about his involvement in the disability rights movement and if he was here today, what do you think he'd say, you know, for the growth of freedom?

00:05:11:09 – 00:05:38:22

Damian Griffis

Well, Uncle Lester Bostock is a hero, really, of a movement with disability. And just last week we had the fifth anniversary of his passing, and he was an extraordinary leader. And I was very humbled to be mentored by uncle and I miss him all the time. But it is a great man, a great leader. He among many things that he changed in his life.

00:05:39:09 – 00:06:14:13

Damian Griffis

And he was the person who highlighted for the first time really what was known what he called the double disadvantage of Margaret Disability. So the fact that many First Nations people with disability experienced discrimination based upon their race and disability was something that he talked about way back in the 1990. So he was an absolutely fearless advocate and a man with disability himself who and also I knew personally some of the challenges that many with disability faced.

00:06:15:03 – 00:06:40:22

Damian Griffis

I think one of the things that was really great about Arthur Lester was he was such a proud, strong Bundjalung warrior. He was a beautifully humble man and also achieved a lot in the media, as you would know. And he was a pioneer of First Nations media in many ways, and he also was very involved with Black Theater, very involved in the 1967 referendum.

00:06:40:22 – 00:07:04:02

Damian Griffis

And I think he would be proud of where we've got to, you know, over the last 22 years we started we still we didn't get funding for a long time, but in the early days and Uncle Lester volunteered his time. And then we just had a couple of desks in an office at Redfern with which we shared with people Disability Australia and they were a great help to us.

00:07:05:07 – 00:07:31:08

Damian Griffis

And then when I think that we now have gone from is voluntary time

just to small businesses to begin with. And then then Jenny joined us and Lai Ha we went from volunteering really to where we are today, where we have staff located all around the country I think can be very proud of that achievement and and but amazing every day we all miss him.

00:07:32:04 – 00:07:51:04

Damian Griffis

A beautiful man, a very, very strong leader that had such humility about him and his love for others. So really, I admire him all the time. I think about it all the time. But he lived a life for other people, was a selfless man, you know. So.

00:07:52:18 – 00:08:24:11

Bernard Namok

Yeah, I, I heard an interview that she did back in 20 just before the royal commission started, mentioned something about, you know, the Disability Royal Commission. It was a big part of FPDN and focus. And, you know, with all the series of public hearings that we've been, you know, here to see about and, you know, to heard violence, neglect, abuse and also exploitation with people with disability.

00:08:24:11 – 00:08:38:19

Bernard Namok

As a CEO of First People Disability Network, what are some of the what are some of the things that you would like to see change for a mob with disability and also their families as well?

00:08:40:00 – 00:09:07:11

Damian Griffis

Yeah, I mean, the royal commission has been really distressing a lot of the time to hear the stories, as you know, Bernard. And, you know, unfortunately, first nations people with disability, you know, most Australians with disability, for that matter, are very vulnerable to abuse, you know, and it's a it's a very sacred thing in many ways. It doesn't really get talked about in wider Australian society.

00:09:07:11 – 00:09:37:20

Damian Griffis

So the Royal Commission has been really important to expose some of those things and I'm really concerned about and you know, I still don't think most decision makers in government and stuff really have much of an insight into how much poverty exists among many of our communities and the day to day struggles that many with disability face, you know, just sort of living day to day, to be honest.

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Damian Griffis

I also think that we need to return to our old ways of supporting each other and community. And I don't mean I think we have a lot to offer. And the wider disability rights movement, as you know, there's no word that compares to disability in our traditional

languages. And that's a beautiful thing because it shows that we don't label people.

00:10:01:19 – 00:10:23:16

Damian Griffis

We don't we take them as we find them, you know, and that's something that we should be very proud of and in fact, we should be sharing with the rest of society. In a way, I'm really concerned about the situation in relation to justice issues. You know, the royal commission's been hearing a lot about some of those issues.

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Damian Griffis

You know, we still have police and the justice system that doesn't understand how to support First Nations people with mental illness or what's referred to today as psychosocial disability. I think that's a major concern, really worrying. And the lack of access to early intervention, support for a lot of our young people with disability. You know, if you can get support at a young age, you can have it.

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Damian Griffis

You know, things can work out very differently for you. You know, we still have an education system that discriminates against young First Nations kids, be it institutional racism or idealism. So there's many issues that we really need to continue to speak out loudly on. And I think that's one of our challenges going forward, continue to really speak up loudly and get more and more of our mob with disability, speaking for themselves in a really loud and proud way.

00:11:20:11 – 00:11:30:06

Bernard Namok

He also December 3rd is International Day of Persons with Disability. What is your message to the listeners of Yarning Disability?

00:11:31:11 – 00:11:57:16

Damian Griffis

It is is great phrase and it is, you know, it's using international disability rights. So it's nothing about us without us. So and that's the same principle here. So the international movement led by Disabled Peoples International came up with that sort of phrase. And I think it's really powerful in the sense that we have to give voice to disability.

00:11:57:16 – 00:12:18:23

Damian Griffis

They themselves are they're experts in their own lives, of course, and and that's our role is to make sure that Mark Disability feels like they've got a voice. If they're not confident in speaking up, that they know First Peoples Disability Network will speak on their behalf if they're happy for us to do that. But we really have to be

about giving voice most.

00:12:19:08 – 00:12:38:07

Damian Griffis

And that's what's so great about this podcast that you're doing better. I think we're going to get a lot more opportunity to promote disability telling stories, and I think when people tell their stories, it can also be really helpful for other people to hear, you know, like this might be how, you know, got through an education system that was really hard.

00:12:38:07 – 00:12:46:04

Damian Griffis

Or this might be, I think all those things are really powerful and I think this sort of communication is really vital. So yeah.

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Bernard Namok

And also lastly, what is one unique thing about FPDN

00:12:51:13 – 00:13:12:20

Damian Griffis

Yeah, that's a great question. Well, I think I think the fact that our board are all First Nations people with disabilities sales is obviously means where any individual is disabled people's organization. So that makes us very unique in Australia and even in the world actually. So and that most of us does have disability themselves or a very close personal connection.

00:13:12:20 – 00:13:34:16

Damian Griffis

So I think for all of us it's very personal. You know, we're all very committed to the work because we we know how important it is and we all have that personal experience to draw upon. And I think that's one of the things that makes us unique. You know, we're not a service, you know, spokesperson necessarily. What we're about is but with disabilities.

00:13:34:16 – 00:13:39:23

Damian Griffis

So and every one of our staff have that personal connection. And I think that's really, really.

00:13:48:12 – 00:14:16:10

Bernard Namok

As the host of the disability podcast, I'll be hearing stories from Bob with disability. So I thought it would be the perfect time to share with you all my disability story. I've never shared my story publicly before because it was an experience that really impacted my life and I wasn't ready to. But as the years have passed by, I now feel it's time for me to share my story in hopes it will inspire others in their own disability journey.

00:14:16:10 – 00:14:43:20

Bernard Namok

I spoke to disability advocate Carly Wallace and told her my story. I was working as a radio broadcaster up in the Northern Territory and working up there for about 17 years before that. So I was living in and working up in Thursday Island and yeah, enjoying life as a young Torres Strait Islander.

00:14:44:03 – 00:14:52:15

Carly Wallace

So what made you want to get out of radio but then also come to a place like FPDN to become a disability advocate?

00:14:53:04 – 00:15:24:09

Bernard Namok

Though some life changing means situations happening in my family and I was living over in the Northern Territory and my brother had an experience that made him travel from medevac from Central Island down to Townsville and my brother had rheumatic hearts and it didn't take one of his medication that allowed his blood to be thin, the cause blockages on his brain.

00:15:24:09 – 00:15:54:06

Bernard Namok

So he had to be flown down from his island to Townsville and I think, you know, living and working over the Northern Territory, I wanted to be close to the family and I guess, you know, at that time there was a lot of deaths happening in my family too. I lost my auntie, my best mate from school, passed away.

00:15:54:06 – 00:16:26:04

Bernard Namok

I was living over in the Northern Territory and my brother had that operation. Some of the things that happened to, you know, my mum at the hospital here in Cairns, which kind of question things, you know, and I know from doing radio broadcasting is, is, you know, you have to have some sort of interpreter with, you know, first nation just to break down a lot of questions and stuff.

00:16:26:04 – 00:16:36:22

Bernard Namok

And yeah, so I started asking questions to one of those social workers in at the Cairns American Hospital and. Yeah, and then it kind of happened from then.

00:16:37:08 – 00:16:55:12

Carly Wallace

Hmm. So this experience with your family has then kind of triggered you to want to go back home. What? Why? Why, as a First Nations person, is it important for you to be near family when something like a disability journey happens.

00:16:56:16 – 00:17:29:04

Bernard Namok

And this to guide family within this because this is all new to us

growing up. You know, I know a lot of families that have experienced disability, but when it happens to your family, my family, it kind of changed the whole situation. And I guess, you know, my mom is the only person that we have because, you know, my dad isn't around to me to help us.

00:17:29:18 – 00:18:03:02

Bernard Namok

So I think, you know, taking that load of my mom and my sister and being here with with them and kind of guiding through them with and helping them to, you know, with my brother's appointments stuff that my brothers, my brother need. So I have to make that decision to kind of resign from something that I used to love doing and moving over and being among family, which is a whole new world.

00:18:03:06 – 00:18:33:02

Carly Wallace

Many people probably wouldn't know that you have your own disability story that you'd like really never spoken about before. I know you've spoken privately about it with your family and friends, but you know, when you were living in the territory, you did go through your own experience. So take me back, I guess to I think it was around 2011 when you were living in in Darwin and you your health started to kind of decline.

00:18:33:02 – 00:18:38:13

Carly Wallace

Can you take me back to that? What did life look like before any of this stuff happened? So in Darwin, paint me a picture.

00:18:38:22 – 00:19:29:05

Bernard Namok

Everything was normal. I moved over the to great traveling actually in the remote communities I remember going up to says the island 2010 for for a remote to media festival. And when I returned back to to Darwin I started feeling a bit off whenever I eat or drink and I would vomit everything back up. But I was still traveling across all the remote communities up there in the Northern Territory and I think what stuck in my memory is when me and a few workers from the radio station traveled out to West Arnhem Land and traveling out there passing Killa Crossing, which is one of the most notorious crossing that, you know, give way to crocodiles

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Bernard Namok

and and stuff, you know. And I remember that trip that I had to tell one of my workmates to keep stopping because I always went to vomit going out. I was weak, but I was still out there doing radio broadcasts and after broadcasting it was in a hot sun and I had a jumper on. I remember that there was a picture of me standing and it was, I think around August, it was around August and August, I think.

00:20:01:09 – 00:20:09:20

Bernard Namok

And around that time it's Darwin's pretty as long that person was walking around in jumper wet season.

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Carly Wallace

Which makes no sense.

00:20:11:22 – 00:20:40:13

Bernard Namok

And I kept on traveling out. But then that particular trip when I went back home after coming back from west Arnhem Land, I think the only energy that I had, I had one of my best mate Gilly living with me at that time and the only thing I remember, I think he helped me and walked up the stairs and I just laid on that in the lounge and no fan, nothing.

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Bernard Namok

Everything was off. It was August and I had like two or three layers of quills.

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Carly Wallace

So that's kind of when you knew, like, something's not.

00:20:49:17 – 00:21:10:15

Bernard Namok

Something's not, right? Yeah. And there's so much carnival that one can take. So he looked at me like, Nah, nah, let's go. Let's just one time go hospital, you know? So we went to the emergency. I think it must have stay there for like a couple of hours. And then the last thing I remember was one of the nurses said that they can't see us until the next day.

00:21:10:22 – 00:21:24:06

Bernard Namok

I said to my mate, Come on, let's just go. So when I just when I got up, the last thing I remember was him catching me because I had seizures. And then the seizures was the start of multiple seizures.

00:21:24:14 – 00:21:32:19

Carly Wallace

What happened since you had those seizures? What happened then in the next few hours and days? Well, because obviously you don't know what you probably been told now what's happened.

00:21:33:03 – 00:22:00:20

Bernard Namok

So my mum and so my aunties went over to Darwin and what I was told from my mom when she walked to the emergency room I think, and yeah she's just seen pipes and cords coming out of my mouth helping me to breathe. I was in a I wasn't able. Yeah. What I was told I was in a coma for a couple of days, I end up having meningitis.

00:22:01:04 – 00:22:25:18

Bernard Namok

Doctors ended up telling my mom from what I was told by my mom, is this prepare for the worst because I don't know what's going to happen when I wake up. Whether I was going to be in a vegetable states or I'll need a full time care. But my life wasn't going to be the same as how I lived for a little while before I went into the hospital.

00:22:26:02 – 00:23:03:13

Carly Wallace

Before this, your house, a broadcaster traveling around the Northern Territory to remote communities, just living your life in Darwin. You're a fit and healthy person and then you start to feel sick and then overnight basically you're in an induced coma and now your family rushing to Darwin to be with you and told while you're incapacitated in an unconscious state, that your going to be either not surviving to be disabled or not sure what's going to happen.

00:23:03:13 – 00:23:15:24

Carly Wallace

Yeah, meningitis is really serious and you know, that can happen to anybody and you can kind of pick that up and you've picked it up. When you woke up, what do you remember in the following days and weeks from that.

00:23:16:12 – 00:23:54:15

Bernard Namok

And few years? I'm like, What's my mom doing here in Darwin? I was like, okay, I'm lying there and I see my mom, I see my aunties, I see, you know, my sisters. And I'm confused by those certain things that I know that it didn't feel right. For example, like I think I asked for, I was thirsty. And then when I went to drink from the juice or sippy cups, I missed myself because my left side of my face had a the effect of because I think I had smell.

00:23:54:24 – 00:23:56:19

Bernard Namok

It was not pretty much.

00:23:56:24 – 00:24:01:14

Carly Wallace

Was it was it scary? Was it like confusing? Like what did it feel like?

00:24:01:14 – 00:24:30:16

Bernard Namok

Confusing. Confused because why? Why is half side of my face is not working properly? Pretty much. I had to learn everything from the beginning. I had to learn because I wasn't talking properly. I kind of slurred in my sentence. I couldn't walk, so I had to be lifted up to go to the bathroom. I had two nurses, you know, supporting me to to do everything.

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Bernard Namok

And then that part of the rehab kind of started from there. But, you know, like trying to walk, trying to talk and then trying to do everything. From the beginning, I had to do a lot of that stuff from the beginning.

00:24:46:07 – 00:25:04:17

Carly Wallace

That just goes to show that I guess, you know, your experience at disability can happen at any time to anybody. That type of journey in life can change so quickly. How long were you in hospital for and how? Tell me about that rehabilitation process.

00:25:04:23 – 00:25:33:03

Bernard Namok

I got given this wheelchair and trying to do a lot of things from the start is pretty much yeah, it's it's hard, like when you're trying to at that age I think I was like 20, 27 or 28 and trying to do a lot of things from from the beginning. But the rehabilitation process, what kind of made me push myself was, I guess the person I am.

00:25:33:10 – 00:25:57:00

Bernard Namok

I got pushed out from my ward down to in front of Rhode Island Hospital, and I was put into a row with other people going over to the rehab. I wanted to push myself because, you know, going over to rehab, it was like we have to identify animals, you know, like from a book that was part of my rehab because I didn't have no knowledge about anything.

00:25:57:05 – 00:26:20:05

Bernard Namok

So I had to I know, like from one of the rehab activities, I had to identify animals. What color? So it was that pretty much from the beginning, what color is this? What shape? And then there was other days when I had to catch catch on to them bars and kind of walk being supported with workers.

00:26:20:11 – 00:26:25:23

Carly Wallace

Is your mind like changed at any point to go oh I'm I'm I've got a disability right now.

00:26:26:07 – 00:26:55:07

Bernard Namok

I think when one of my workmates was feeding me in hospital this is prior to rehabilitation, she was feeding me and I was getting ashamed because she's my workmates and for her to feed me, I felt yeah, I just felt shame. But then she kind of reassured me that that's okay. You know, we're family because that's what family do.

00:26:55:12 – 00:27:19:18

Bernard Namok

Once I was told that, then I couldn't accept accepted. But after going through rehabilitation, I had no memory of what happened. So over the years, like certain memories have come back to me, but during that time, like my mum was my, my mum had to be there in Darwin and then my two sister was there to support mum.

00:27:19:23 – 00:27:33:21

Bernard Namok

I think one thing good about being in radio broadcasting is, is talking and I think when I went back to work after being in hospital, I went back to work mid-November now.

00:27:34:03 – 00:27:53:11

Carly Wallace

So yeah. So you not only, you know, the prognosis was you're not going to either survive, you're not going to recover, you're probably going to be in some type of state for a long time for you to then go through hospitals, slowly get better. You've come out of hospital, but you're still doing a rehab attached to the hospital.

00:27:53:19 – 00:28:19:10

Carly Wallace

And then you decide, Oh, I. Is there a reason why you went back to work? Like like obviously, like life keeps ticking, right? Like, why are you being while you're in this disability journey? Were there any systems like that kicked into place for you so you could have that time? Or did you have to go back to work because, you know, you earn the money, you got to pay rent, you've got to do those things.

00:28:20:02 – 00:28:24:11

Carly Wallace

Did anything kick in for you like a disability support payment and and things.

00:28:24:11 – 00:28:50:24

Bernard Namok

Like nothing because I'd I'd worked up I worked up I think a couple of hours enough to cover rents for the amount of time. I remember going into the Centrelink in Darwin. This is like when I was released from hospital, I had to go and kind of sort out disability allowance I think. Well, disability pension.

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Carly Wallace

Payment.

00:28:51:22 – 00:29:20:10

Bernard Namok

Yeah, yeah. Support payments like my work wages was just about to run out, so I had to get to have some sort of money, you know. And then I think I had an episode in where I think I was going to, you know, because being in public I thought I was going to have a fit.

But luckily I can sit down and couple of staff members came and give me a glass of water and they wanted to call the ambulance but didn't want to make a scene.

00:29:21:02 – 00:29:21:13

Bernard Namok

So they say.

00:29:21:22 – 00:29:47:05

Carly Wallace

This is a month off. People like think basically you just got out of hospital and you're like, well, I've got to take some more leave because I'm not recovered. Like I'm, I'm recovering. Yeah. Walk into Centrelink because no one's coming to me, no one's helping me with that process. So I've got to go and find out how I can get payments to try and like working late because I'm disabled from doing my job from life right now.

00:29:47:21 – 00:30:00:15

Carly Wallace

And then you've had to walk into Centrelink and that was a miracle in itself that you were able to actually go in there and then, you know, you're feeling in that pressure of that, you know, you're in the system and people are talking to you and there's crabs and there's all these.

00:30:00:15 – 00:30:01:00

Bernard Namok

Yeah.

00:30:01:16 – 00:30:13:14

Carly Wallace

You've just been isolated in hospital for three months and now you've got to try and navigate a system that should have really been there for you. And that must have just been crazy. Hey.

00:30:13:22 – 00:30:29:17

Bernard Namok

Yeah, it was full on, like. And in the end, I didn't. I didn't end up getting disability support payments. I end up going back to work. I was improving and yeah, I was improving enough to go back to work part time.

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Carly Wallace

Was that because Centrelink told you or the system told you or is that because you said, Oh, I feel a bit better, I'm going to go back to work?

00:30:37:03 – 00:30:39:03

Bernard Namok

I felt a bit better.

00:30:39:07 – 00:30:42:11

Carly Wallace

What impact is this having on your family and your friends?

00:30:42:16 – 00:31:07:06

Bernard Namok

The impacts from that, from that experience? I guess always looking out for me, asking if my mom was still asking if I'm okay. Like I'm almost 40 now. If I go out like, well, where are you going? You know, like just being that extra cautious, you know, like when families are around us come August, you know, like during that particular week, I have no memory.

00:31:07:06 – 00:31:14:07

Bernard Namok

And that's when I tend and I still shut down and shut away from everybody. I still do that.

00:31:15:03 – 00:31:37:06

Carly Wallace

So at that time, like, it must have been so stressful. Like your mum's left the Torres Strait to go to Darwin to be with you. So you know, you've got mum in the house, you've got all these people you're trying to recover and she's thinking then like how her, her life's probably going to be impacted right. Like your family friends at that time.

00:31:37:06 – 00:31:53:18

Carly Wallace

Like I think a lot of people probably didn't even not you wouldn't have even realized the ripple effect of like what's happened to you and then how it's been affected, your family and your friends, colleagues, your work loss. Did you think that life was ever going to go back to normal?

00:31:53:22 – 00:32:11:04

Bernard Namok

I think when I was in hospital, I did I went I thought, okay, so I have to move back to the island. But how am I going to move back to the island? But I didn't think that it was going to end up like that. I don't know how or why. I just thought that I'm going to make a recovery.

00:32:11:10 – 00:32:40:14

Bernard Namok

That was my thinking back then, that I wasn't going to go back to the island. I told my mum, that's okay. Like you can go back to to the island like I'm going to be a roach, I've got my workmates, yeah, and I've got nights, so I'm going to be alright. So she ended up there and my two sisters ended up leaving Darwin to go back one week before I was discharged from Rhode Island, Saskatoon.

00:32:40:23 – 00:32:46:22

Carly Wallace

So you ended up making a full recovery. How long after you got

discharged, you think?

00:32:47:05 – 00:33:06:23

Bernard Namok

I was driving December and saying and doctors were saying that I'd probably I wasn't going to do the things that I was doing before I was going into hospital. So if I was driving, there was no way that I was going to go back driving again because of what happened to my brain and everything else that happened when I was in hospital.

00:33:06:23 – 00:33:41:08

Bernard Namok

And for the amount of seizures, doctors wasn't sure that I was going to be able to go back to work full time or drive. So I was back to catching a bus and I said to myself, I'm back to catching a bus. I don't want to catch a bus. And then December come around. I passed. I passed, you know, the the medical I had to get a medical tick, you know, from the doctors and from the rehab that came in and, you know, assess my workplace and the units.

00:33:41:19 – 00:33:51:07

Bernard Namok

If I was doing everything, you know, up to standard and I got the tick and I was back driving again December of that same year.

00:33:52:02 – 00:33:58:20

Carly Wallace

And then you were back on radio as well as a broadcaster like in December or like around then or.

00:33:58:22 – 00:34:12:23

Bernard Namok

Around November and up doing part time. That's the time when I was catching a bus to and from from work. Come December I was back, back doing my mornings the following year. And when you started back work in January.

00:34:13:05 – 00:34:33:00

Carly Wallace

Have you ever thought like, you know what, if I didn't recover, what would my life have been like? You know, thank goodness. Like you're all your, you know, you're back to kind of being battered by over these last ten, 12 years. But what have you ever thought about that? Like, what if I hadn't recovered? Like, what would life have been like for me?

00:34:33:10 – 00:35:01:09

Bernard Namok

I think the first couple of years when I came out of hospital, I think it was one of the hardest. Like every August, I usually have that thinking, What if I didn't recover? Or What if I didn't push myself into doing the thing at rehab or What would life be like if I had to go on full time care?

00:35:01:22 – 00:35:06:13

Bernard Namok

And doctors did not have a pretty much surprise on how quickly I might recovery.

00:35:06:16 – 00:35:22:24

Carly Wallace

I think they they must have underestimated a strong black man to go. Yeah. Medically in this. Well, we're going to tell you that this is not possible. You know, that's probably the general consensus when, you know, things like meningitis and these types of viral infections happen that.

00:35:22:24 – 00:35:23:08

Bernard Namok

E.

00:35:23:19 – 00:35:47:22

Carly Wallace

And I can just like we say it can happen to anybody and that the odds of beating that is really rare. So for you, you know especially I guess also being first nation personal, you know, Aboriginal and Torres Strait Islander person now has plastics medically in that world are not good. So, you know, you're already behind the eight ball, I guess, in terms of the the medical western science.

00:35:47:22 – 00:35:58:19

Carly Wallace

So but I think that's the power of, you know, mob. Hey like yeah what we made with colonization and trauma and the stuff filters down into this resilience.

00:35:58:19 – 00:36:24:01

Bernard Namok

Yeah. And one thing that's like, oh they use kind of forget, you know, I'd forget it. But the situation or the experience, what happened to me back in 2011. But every time I go back to the hospital, I kind of it triggers my memory again of what happened. So I remember going back to the hospital to do as I broadcast for work and we're out of all places.

00:36:24:01 – 00:36:47:10

Bernard Namok

It was at the main entrance of Royal Darwin Hospital and at that time there was people that was mob being escorted down to jump on that bus to go to rehab. And I don't know why, but the fallout that was driving the bus, I remember I remember him because he was I followed that he used to drive me to rehab.

00:36:48:01 – 00:37:08:05

Bernard Namok

And I walked over and I tapped him on the shoulder and I said, I don't know if you remember me, but I was a patient that used to take over and it kind of triggered his memory, too. And he remembered

what was is I remember you. You're that young fellow that used to I used to take over to rehab.

00:37:08:17 – 00:37:29:03

Bernard Namok

This was a couple of years ago and he was pretty surprised on how much recovery I made. And he said, you look like nothing had happened to you. But yeah, it was like, yeah, but you know, that memory kind of like every time I go back, it kind of triggers my memory of what happened and I think it was good to go back.

00:37:29:03 – 00:37:48:10

Bernard Namok

As for healing too, because that when I see him and all those patients that was being what was waiting for that bus because that was one of them, I had to be waited in line. And then they used to push us up on that escort thing and then push into the bus and then taken over to rehab. So I was one of them.

00:37:48:10 – 00:37:56:24

Bernard Namok

And then when I was doing a broadcast, yeah, kind of went up and talked to him and yeah, he remembered who I was.

00:37:57:10 – 00:38:16:01

Carly Wallace

That's an amazing life reflection, I guess. And being able to look back from that journey and like what you've gone through, it's a it's a disability journey. I think that a lot of people wouldn't, you know, necessarily think, oh, we think of disability, I guess sometimes as permanent.

00:38:18:05 – 00:38:24:23

Carly Wallace

But journeys like this is, you know, this is a story that can, I guess, happen to anybody, anybody.

00:38:24:23 – 00:38:25:06

Bernard Namok

And.

00:38:25:14 – 00:38:34:17

Carly Wallace

You know, it has changed the tragic trajectory of your life in a little ways. Like how do you how do you live your life now that you've gone through that experience? What's it taught you about life?

00:38:35:03 – 00:39:01:05

Bernard Namok

I guess to appreciate life to be I guess, you know, involved with family more not to put work on the top always I think because I was always working and not only from my experience, like from my brother's experience too, like I think, you know, it was time to be

it could be be close to family.

00:39:01:11 – 00:39:10:03

Carly Wallace

What does that experience taught you now that you're disability advocate, how do you see things now from that perspective? Now working at first people's disability Network.

00:39:10:09 – 00:39:25:21

Bernard Namok

I'm kind of like I have lived experience and I kind of know what should be in place, how I smoke should be treated. You know, when we're in that world and I guess listen to some of.

00:39:26:13 – 00:39:34:23

Carly Wallace

What needs to change for for systems to better equipped and more if their lives changed overnight like this with a disability journey.

00:39:35:04 – 00:40:12:13

Bernard Namok

I think having somebody there especially in Darwin like there was always like a medical Aboriginal liaison officer and I'm always around and around my, my breaking things down and you know, if there was like a doctor coming around that would do that weekly, you know, one day checkups, you know, there would always be indigenous liaison officer there to be the support for family because especially for my experience, like my mum and family, they didn't go through that experience before.

00:40:12:13 – 00:40:52:07

Bernard Namok

So that world was pretty new to them and but having someone there to break things down to grassroot level so they'd have a better understanding about things, you know, and if I were to compare, you know, like that experience that I went through and what I've seen my brother's experience, yeah, I think my mum would have had more, better understanding about what I've been through and what system, what things are in place, you know, over in the Northern Territory and things are pretty new to my mum but they're here like I got to see firsthand on nothing being explained to my mom properly, you know.

00:40:52:07 – 00:41:06:12

Carly Wallace

And it's these systems that are there that are stopping families from accessing really to to what they should be talking about it now like for the first time I guess has been how has this made you feel about telling your story?

00:41:07:07 – 00:41:28:20

Bernard Namok

Well, you know, what's like for the last 17 years or for the last probably 15 years, I was dealing with that experience alone in the

Northern Territory. But for the first time last year when I was living here in Cairns because I was surrounded by family, I didn't go through the experience as bad as when I was living over in the Northern Territory.

00:41:28:23 – 00:41:52:24

Bernard Namok

When I was living over in the Northern Territory, it affected me more. But then for the first time when I moved back to live among family here in Cairns, I didn't go through that as much as times when I used to live breaking down. Yeah, probably because I was living around family or I think it was, you know, like a side of me moving on, I think.

00:41:53:06 – 00:42:01:20

Bernard Namok

And I didn't, I didn't like dwell on that as much. I yeah, I didn't dwell on that as much as when I was living over in Darwin.

00:42:02:02 – 00:42:10:19

Carly Wallace

Yeah. Why is it important for more with disability, I'm up to talk about, you know, their stories and, and of disability.

00:42:11:01 – 00:42:28:02

Bernard Namok

I think it's about healing because when I started talking about my because I've kept on didn't want to talk about it when I first come out of hospital, I was always like, Yeah, I don't want to talk about it. But then when I started to talk about its economy, help me to move past that situation.

00:42:28:10 – 00:42:42:12

Carly Wallace

I guess all the people to probably, you know, could relate to like a story like yours and others where, you know, happy to see you healthy and happy and, you know, living your life. And now you're a strong advocate for others side. Thank you for telling your story.

00:42:42:15 – 00:43:27:11

Bernard Namok

No worries. Thank you for. Thank you for listening and thanks for listening to yarning disability if and would like to thank you for coming on this journey. As each week we hear from First Peoples living with their disability and shine a light on the issues they are facing. I'm your host Bernard Tomic Junior follow FP on our social media accounts stay up to date with feature episodes and information, and also visit our website at WWE that FP and that all you.