**Interview with Penny Dorgan and Liz Wright**

Liz

This is a Women with Disabilities Victoria podcast.

We acknowledge that these podcasts were recorded on the traditional lands of the First Nations Peoples of this country. We acknowledge their Elders, past, present, and emerging. We acknowledge that sovereignty has never been ceded, and that this is, and always will be, Aboriginal land.

From the Outskirts is a series of podcasts featuring women with disabilities who live and work in regional Victoria.

I’m Liz Wright, a disability activist and advocate. I’m also the Manager of Community Inclusion and Women’s Empowerment at Women with Disabilities Victoria.

All the interviews were recorded in each person’s home or workplace, so from time to time there is unexpected background noise.

We hope you enjoy.

Artist Penny Dorgan talks about her passion for creativity, her work in the disability sector, and her focus on making an impact on systemic issues.

During this episode there is mention of depression, anxiety, and mental health, please take care and if you need support or assistance, please call Lifeline on 13 11 14.

Penny

This is Penny Dorgan, and we're on Wadawurrung Country, and we pay our respects to past and present leaders and future and emerging ones.

Liz

Hi, Penny. It is so lovely to be here in your home, your beautiful home with your beautiful, beautiful pets around. We were welcomed so joyfully by Red. That was lovely.

Wanting to talk to you today about your life because you're a very interesting woman to us, and I'm sure you're going to be a very interesting woman to our audience.

Can you tell us a little bit about your story? Where did you come from? Where did you grow up?

Penny

So, I grew up in Fyansford, which is literally just about 10 minutes from here. I grew up on a hobby farm. My parents wanted to raise us on a farm. We went to a little tiny, good country school at Fyansford. And then I went on to Clonard College and to Geelong High, and then I furthered my education at Gordon TAFE and then I went on to RMIT and did a Bachelor of Applied Science.

Liz

And what was your Bachelor of Applied Science wanting you…like where was it going to lead you?

Penny

So, it was majoring in intellectual disabilities. So, it was increasing my understanding in human services and the disability sector. So, I've worked in disability sector for over 27 years.

Liz

Was the course everything you wanted it to be?

Penny

Absolutely.

Liz

Oh, that's a that's very good recommendation then. So, if you've worked in disability for over 20 years, obviously mainly with intellectual disability?

Penny

No, a whole range of disability, my favourite and most endearing times where with high needs people, so people with cerebral palsy or motor neuron disease or children with chronic complex and medical needs. So, a lot of my training was done through the Royal Children's Hospital so I could do both oxygen, PEG feeding and other sorts of support needs that they may have had.

Liz

So, is it more around kind of holistic health care or was it also around companionship and friendship when you were working with individuals?

Penny

For me, it was in impeccable care, so ensuring that participants had their care met on a daily basis, but also that they had the opportunity to experience community life with you auspicing and being beside them to integrate into the community.

Liz

Oh, that sounds like the type of worker everybody needs. That sounds like a kind of dream career if that's what you'd always wanted to do.

Penny

Absolutely. There were steppingstones, so I started working at the City of Greater Geelong as a high needs carer. Then I moved into Gateway Support Services and did holiday programs for students that were aged six through to 18. And then I was part of the Interchange Host Program, which is one of 16 programs over the state where we're matching a child with a disability with a volunteer for one weekend a month.

Liz

Does that program still occur?

Penny

Yes, it is. It's sitting under Gateway Support Services for the Geelong region.

Liz

Oh, wow. Did you ever suspect that all of this training and that your desire to work in disability would ever be something that would culminate…it didn't culminate...it didn't cause or make anything happen…but you ended up with a disability.

Penny

Yeah. No, I didn't feel that that would be the case. I knew I was unwell as a child growing up there were always unanswered questions about my health and chronic illness. But as life went on, complexities happened and unfortunately, I was diagnosed with catastrophic antiphospholipid syndrome, which in layman's terms basically means sticky blood syndrome.

So, my blood is too thick and sticky to transport oxygen to the organs, so I need to top up on oxygen and I'm a stroke candidate. So, basically, I have mini strokes often, but I've had two major strokes in my time as well.

Liz

When you say mini strokes often, like, what does that look like? How does that appear for you? In layman's terms - I don't know how that works.

Penny

It can be days you have more fuzzy capabilities of undertaking daily tasks or getting strategic about being able to work through your day in a chronological order. Or it might be my speech is impaired by the afternoon where I'm tired and fatigued and there's a bit more activity going on, or there might be days where I'm more jittery or jolty and there's some neurological defects going on.

Liz

Do you have a health care team around you, like generally, most of the time?

Penny

I have a very complex health care team around me, and it's taken me all of my 48 years to get the right people in the right team. And at the moment, I would say I'm probably the best I've been in the last 15 years.

Liz

Wow. And is that because you've been your own best self-advocate?

Penny

Absolutely.

Liz

And do you think that's because of your scientific background?

Penny

It's because I've pushed for the right medical team to be on board. Because I've never given up and my glass is always half full.

Liz

Yeah.

Penny

And I'm always optimistic. It doesn't matter what disability you have, there's always barriers, but those barriers can be lifted if you think about the problem and solve it in a different way.

I think systemically we can work together and create a universal community for all of us. So, it is a seamless steppingstone into the community and that you don't have to take your ramp everywhere to get into one step, to get into a shop, that everything's seamless and accessible because people in industry, like local community and state and federal are all on the same page.

Liz

Well, they need to be on the same page. We need that to be a priority. You know that we don't have built public buildings and spaces and places where some people can go, and some people can't.

Penny

Exactly.

Liz

So, after you've finished studying and started your work in disability, you know, you've been passionate about a few things. What are you passionate about?

Penny

My main focus in life is wanting to make a difference. So, when I was a disability carer, I also was an Interchange host, even though I was working for Interchange as well and I just wanted to make a difference. I just wanted to be able to make changes individually in my own backyard, but also reach out in committees and other changing places to be able to systemically build a place that is for all, so people feel welcomed, and they don't feel that they have to apologise for their space or place and that they are all one as one community.

I think lately my biggest asset has been being matched with my assistant dog, Red, and he is amazing. He puts washing in and out of the washing machine for me.

Liz

Yeah.

Penny

He brings the trolley with the washing in it to the air dryer and allows me to hang it up one by one. So, he passes that washing to me one by one to my hand.

Liz

Yeah.

Penny

So, I just have to finish off the task. And that's all energy conservation for me because I run out of energy by the end of the day…

Liz

Yeah.

Penny

I fatigue out.

Liz

Yeah.

Penny

And he opens and shuts doors and gates. He picks things up off the ground for me. So, if I say switch when we're out, he puts his paws up and pushes the traffic lights button.

Liz

Oh my God.

Penny

So, I don't have to do that at all. And that and that's a good thing for me because I'm so auto immune suppressed, any, any surface that I touch is a risk of infection. So that takes away the stress of public touching places…

Liz

That incidental sort of stuff that lots of people have had their hands on.

Penny

Absolutely.

Liz

What about shopping when you go shopping?

Penny

So, Red helps me with the two bottom shelves at the supermarket.

Liz

Yeah.

Penny

So, anything on there, I get a grab stick and pull it onto the floor of the supermarket, and he picks it up and puts it into my lap so I can put it in my trolley. Also, through COVID and through some experience, some negative experience I've incurred, I had some mental health concerns…

Liz

Sure.

Penny

That I've had to battle through being in hospital with mental health on a number of occasions where I had to learn to live back in the community with some of my struggles.

And Red has been the answer to my anxiety and depression and to be able to access the community, he allows me to freely access the community without the anxiety that I exhibit.

Liz

You know, anxiety was huge for a lot of people during COVID, and they're doing documentation and data collection around that right now. But if you're talking about anxiety, depression, as well as other disability on top, that must have been a really terrible time for you. But having Red here now, it must be like, liberating.

Penny

It's funny you say that. Even though I was struggling through COVID, I still wanted to reach out and make a difference. So, I signed up to a few…

(laughter)

Liz

I know you going to say some great stuff…

Penny

To the Black Dog Institute body mapping programs and research.

Liz

Yeah. Yeah.

Penny

So, because I'm very artistic, I decided that body mapping would be a very visual and good exercise for me to partake in, but it also would be helping other people at the other end when they're looking at the body maps and reading how influential different things are in your life to, to, to de-stress and to be able to work through your mental health challenges.

Liz

What does a body map look like? So how does that work?

Penny

So, they walk you through…the Black Dog Institute coaches, and they walk through different symbols or different things that would be meaningful for you that make a difference?

Liz

Yeah.

Penny

So, I drew a person, a silhouette of a person in a wheelchair, and then I made that into a jigsaw puzzle because your mental health is all full of jigsaws and you have to put it back together once you've fallen apart.

Liz

Yeah.

Penny

And then within those jigsaw puzzles was the women's colours of green and purple, which strongly resonated. And then there were symbols, like I had snail slippers on…

Liz

Yeah.

Penny

In the wheelchair, in the silhouette. And those snails were that you would slowly retract back out into the community. But if it got too much for you, you put your head in your shell then go back into your…

Liz

Yeah, yeah.

Penny

Little bubble. Yeah. So, there were lots of little things like that. I had the lungs there with all the oxygen going through it, so breathing and Buteyko breathing method and…

Liz

All right…

Penny

Mindfulness…

Liz

Buteyko?

Penny

Buteyko is a method that you use to be able to breathe, usually asthmatics or people with CF or other would learn Buteyko breathing, so you get the air to the base of your lungs.

Liz

Yep.

Penny

Yeah. So, you imagine a string from your nose all the way down to your belly button and you've got to breathe all the way in very slowly to the bottom of that string and then breathe it back out again.

Liz

Wow. So, this is like a practical, yet very symbolic and creative way to reassemble and regroup and look at how you can become the person that you were prior to the depression.

Penny

Yes, exactly.

Liz

Oh, I love it. I I've never heard of it. Thank you for sharing that.

Penny

Yeah, I feel the community still has a great way to go. Stigmatised mental health is unfortunately still rampant in the community.

Liz

Yeah.

Penny

I still feel very self-conscious about sharing, but I know by sharing I can help so many other people along the way.

(Music playing)

Liz

To find out more about Women with Disabilities Victoria go to: wdv.org.au

Liz

So, obviously with mini strokes and the sticky blood situation, you might have to frequent hospital quite a bit. Tell me about your hospital experiences?

Penny

Yeah. So ,since I was in Year nine, I've had regular hospital visits, unfortunately, both for my lung condition, which I am actually in lung failure. So, type two lung failure. Yeah. So, I pick up infections and bugs a fair bit of the time because I'm auto immune suppressed.

Liz

Yep.

Penny

And then I put on 70 kilos plus when I had my mental health breakdown, and I couldn't get that off because I was in a wheelchair.

Liz

Yeah.

Penny

So, I opted to have the last resort which was to have a gastric bypass done.

Liz

Yeah.

Penny

And there were complications with that, and because I had already lung failure and other bits and pieces going on from having had two strokes and swallowing problems and eating problems…

Liz

Yeah, yeah.

Penny

I had to have a PEG tube put back in again, but I had 16 surgeries in 12 months…just to give you an idea… during COVID, that was…

Liz

That’s more than one a month.

Penny

That's more than one a month. I was in and out of hospital so much, and in and out of intensive care with complications. But I really have turned the corner and I'm back on my recumbent trike doing cycling for the Great Cycle Challenge now, trying to get to 120 kilometres, which is my pledge for kids with cancer and better research so that they end up with less consequences after chemotherapy and their treatment growing up.

Liz

So, with the gastric bypass and the recumbent bike, sort of stuff you're getting back, your physical health as well?

Penny

Yes, I've lost 74 kilos.

Liz

Oh, my God, that's amazing.

Penny

So, I've taken off what I put on with my mental health stuff. So, I’m pretty happy with that. But I still have…my goal is still to lose some more weight. So hopefully the bike auspices that weight loss and we can get it still happening over the next six months.

Liz

Well, it's fantastic like the idea that you're raising money as well as using your bike and Red goes with you, and that sounds like a really beautiful and pleasant way to be enjoying being outside again.

Penny

Absolutely. And I have a friend that runs, so she's come along, and she heads off in front of us and sets the pace. And then I'm behind on the recumbent trike, which is also an e-bike. So, it helps me up the hills, so my lungs don't get under too much pressure and then Red trots beside me.

Liz

So, it's like dog paradise really.

Penny

Absolutely.

(laughter)

Liz

Now, I also know that you're a woman of faith, and I would really like to know, if you're happy to talk about that.

I'd like to know, have you always been a woman of faith from a family of faith or just come to it, you know, under your own terms?

Penny

Yes. So, I grew up in a Catholic family and mum was very devoted to her Catholicism. And then at 15, I had a dear friend that was diagnosed with cancer, and she was…had a different faith and invited me to church, her church, which was different to Catholicism, it was Born Again Christian.

Liz

Yeah.

Penny

And I gave my life to the Lord and decided to rededicate myself to becoming a better person through choices and decisions made by following Jesus and his example that he set the world.

Penny

And I just find my deep faith has carried me through some of the darkest times, both emotionally… I had a husband for 17 years and he left me as he didn't want to do disability anymore. And that really sent me into a mental health breakdown…

Liz

Yeah.

Penny

And in my darkest times, even with my medical health, I've been through the death tunnel, what I call where you see the light going to heaven…

Liz

Yeah.

Penny

And I've been told that I wasn't going to survive so many different episodes, but for some reason I've been pulled back and I'm still here today, and I just feel my faith and my strength in decision-making around spiritual affirmations has been the foundation of who I am today.

Liz

Well, you are very generous and very outwardly concerned person, like with the bike, bike, for example, raising money for kids with cancer.

Sometimes people when they're unwell or disabled, it's, it's so much that the focus can only be inward rather than outward. And I think that's a testament, you know, obviously to your outward thinking in your care and your concern for everybody else.

Penny

I think that goes through stages, to be honest. I went through a stage after I had my stroke and then two years later, I was hit by a four-wheel drive on the footpath with my wheelchair and that knocked me back to be going back to rehab again.

And at that stage I was so self-focused, I was actually being selfish to the people around me. Not out of intention or anything but…

Liz

No.

Penny

But just out of trying to regroup myself and get myself back on track, both mentally and physically.

And I had to really work at that. So, I think some people get stuck in their inward thinking about their disability or about their circumstances, that they then fail to see the bigger picture.

I can give an example of one time I was on my way to rehab and there was a crack in the concrete and that really upset me, and I cracked it, and I lost my cool that day. But metaphorically, when I look at it, you can get upset about the crack in the concrete and lose your plot about that…

Liz

Yeah.

Penny

Or you can be thankful that there is a path all the way to rehab that you can actually get to rehab on the footpath with your wheelchair, and you have mobility with your wheelchair…

Liz

Yeah.

Penny

Or you can focus on that crack and…you can lose focus for that whole day and ruin your day because you've been so negative about the crack.

Liz

You're going back to pretty much full-time work. You're going back to work four days a week. That's coming up pretty soon. How are you feeling about that?

Penny

Yeah, I'm pretty nervous about it, but I've been reassured by Latrobe Community Health, where I'll be doing local area coordinator work and I've been reassured that I'm qualified for the job, and I have the skills to undertake what's desired to get an outcome. So, I will be planning with a low to medium plan…

Liz

Yeah.

Penny

So, they won't be complex plans, but they will be plans that are going through the partnership of Latrobe Community Health. So yes, it's four days a week which will be a big shock to the system…

Liz

Yup.

Penny

I'm still expecting myself to run my art business on the side. So, every second Friday I'll run individual classes and every second Sunday I'll run a group class for resin pouring.

Liz

So, talk about your resin work and your creative side here because it's, it's, pretty stunning.

Penny

Yeah. So, during COVID, I decided to cease teaching at the Gordon which I was teaching Certificate IV in Disability. And it all went online, and I really didn't agree with online teaching.

Liz

Yeah.

Penny

Because I would like the personable approach to having someone in the classroom and to be able to orchestrate with the students on a personal level.

However, so, I set up this business and I went through the NEIS Program and set up small business and got myself qualified in a Cert IV for Small Business.

And I started resin pouring. And I was inspired…when I was in hospital so much, I was like: What am I going to do? I'm just stuck in here. So, I googled a lady by the name of Kathleen Steiner-Rice (Kathleen Miller) And she is a resin pourer in America, and she does all her videos on YouTube for free so people can learn off her.

And so, I just Googled and Googled and Googled all of these techniques that she was using. And I thought, I'm going to go home and try that. So that was my next goal, was how am I going to get home so I can try it? So, I kept saying, I'm going to go home and try this. So, I started ordering stuff and things started arriving at the door with my housemates, all the artwork and stock that I needed to be able to pour when I got home.

So, I came home, set up the garage. My cousin helped me set up a spinning pool, which is just a shell clam from the kids from Bunnings.

Liz

Yeah.

Penny

With a spinner cake stand on it. And it helps spin, spin…

Liz

Oh really?

Penny

Spin the bread boards and get the cell activation happening with the chemicals that you need to, to get the artwork out. And I was able to do it quite easily. So, I thought, okay, I'm going to set up my business. And then I thought, okay, I'll join NEIS and do the program. So that took almost two years to complete that. And yeah, now I'm going to go back to work to try and fund some more.

I set up my website…my nickname is Pen Star…I was nicknamed by a young lass who was the sister of a little fellow I was looking after with cerebral palsy, and she came out one day and said: Pen Star!

So that stuck. And I've been called that ever since. So, my business is called Pen Star Art Productions with an S, and I do cheese boards, serving platters, I also do lazy susan's and coasters...

Liz

Pen, you never seem like you're idle. With all your health complications, depression, visits to hospital, teaching, learning, you know, self-learning, the NEIS scheme, all that sort of stuff. What drives your mind to keep yourself so highly stimulated, and creative and caring and outward focused?

Penny

I accredit a lot of my personality to my nanna. She was my love, and very committed to me as a child and we had a very close bond. And she was as stubborn as they come, and I've got that stubborn streak in me…

Liz

Yeah.

Penny

So, never give up, never, ever give up. But I also have wipe out days where I am just on the couch or in bed and I just cannot function for the day. But that's okay. As long as the next day you get up and you put your pieces back together and you keep going.

Liz

Yeah.

Penny

So, always having a diary, planning ahead, trying to work out your next best day because you don't know what tomorrow's going to bring…

Liz

Yeah, yeah.

Penny

So, I always say, if you're going to do it, do it today, because they might have regrets tomorrow.

Liz

What a lovely way to finish our conversation today. Penny, this has been a giant pleasure for me to hear your story, as amazing as it is, has been just a lovely privilege and honour. So, thank you.

Penny

Thanks for the opportunity, Liz.

(Music playing)

Liz

You can view Penny’s artwork at penstarproductions.com.au