Transcript

Lisa Daniel

So welcome, Greg.

Let's start off by talking about the disability that you live with.

What is it called, when it was discovered?

Greg Axtens

I've got cerebal palsy and it affects the way my brain communicates with my body and a bit of my

brain a bit. It's mainly I have spasms every now and then and I think it was discovered in the 18th Century.

Lisa

So cerebral palsy is an illness or a condition that was discovered in the 18th century.

When you say you mentioned that it affects your brain, can you tell me a little bit more about that?

Greg

It affects the connection between my brain and my body.

Lisa Daniel

How does that make itself known? A lack of control of your limbs? Would that be a good guess?

So when you say brain, my understanding is cerebral palsy, which is not much to be honest is that basically your body does not obey what your brain intends, so it's not like you have a disability in terms of your mental aptitude. Is that correct? So your brain works like everybody else's. It's your body that doesn't necessarily play its part the way you would like it too.

Greg

Yes.

OK, so when it comes to you, was that discovered at birth?

Greg

Three months later. My mother, my mother was thinking what's wrong with this baby? And she went to the Royal Children's Hospital, and it took about three months to discover I had cerebral palsy.

Lisa Daniel

So I don't want to ask your age, but let's put you in a decade as it's rude to ask your age.

What decade were you born in 1950s, 60s?

The last year of the 50s
Lisa
Close to me. Why did it take 3 months to diagnose cerebral palsy and is it different now?
Greg
Because we didn't have the same technology. And it takes shorter time to diagnose.
Lisa
Is it true that you can diagnose or you can find evidence of cerebral palsy in the womb these days?
Greg
Yes
Greg, what was your family response to your diagnosis?
Greg
My mother went into fighting mode. And she fought. In the early days she went to every meeting there was on ways to learn about how to improve people with cerebral palsy.
Lisa
So what was she told after you were diagnosed?
What was she told about your future?
Your potential future?
Greg
I may never speak
Lisa
Clearly got that wrong.
What else was she told about your potential in terms of your life expectancy and your quality of life?
Greg
I think she was told that I wouldn't live until after twenty which again was wrong.
Lisa
Is that something that has changed in the current understanding of cerebral palsy?
So if a baby is born with cerebral palsy today, is the life expectancy shorter, or is there just no assumption made?
Greg



I guess she regrets it, but as you say, it's not her fault in that she wasn't told or informed or educated about the possibilities and you know things were different in 1959 and the 60s when you were a primary school aged kid than they are now. And I imagine that when a child is born with cerebral palsy now, there is all sorts of options and education are available for parents, but I'm thinking that if you grow up with television, you have an incredible historical knowledge of TV and popular culture and TV shows of the time.

there is all sorts of options and education are available for parents, but I'm thinking that if you grow up with television, you have an incredible historical knowledge of TV and popular culture and TV shows of the time.
Greg
I remember.
Most people, I know would never remember Ben Casey.
Or Mr. Ed
The Dick Van Dyke Show
Mary Tyler Moore Show.
So on and so on
Lisa
So at that stage was there no kind of avenue for physiotherapy or treatment? Anything like that?
Greg
There was physio but in those days I would say my schooling was a bit of a babysitting service more than an education.
Lisa
In terms of your siblings, are you the only one with a disability in your family?
Greg
Yes.
Lisa
Tell me about your education.
Was there an opportunity to go to school?
Greg
Yeah, yes.
I went to two schools.
Yooralla Balwyn
And a school which doesn't exist anymore

Marathon was a school run by what was then called the Spastic Society. It's now known as an organization called Scope. Most people have heard of Scope.

Lisa Daniel

Tell me about the sorts of expectations that were given to your mum or given to your mum and dad and your family about you when you were say at primary school age was there an attempt to educate properly like other normative kids, because you used the term babysitting before, so I want to draw that out a bit.

Greg

They tried to teach me the basics but I was taken out of school quite a bit to do my physiotherapy

And they didn't, I feel they didn't put the work into me as a normal child.

Lisa

Does there come a point with cerebral palsy where if you don't do the work with say a primary school age kid, that those skills can they not really be learned?

Greg

They thought that the time, but they can do much more these days.

Lisa

So even later if a child with cerebral palsy is ignored at the age of seven and then at the age of 14, can they learn some skills and learn things about their body that they couldn't do when they were seven?

Greg

Yes.

Lisa

So things have changed a lot. What were you told about your expectations for your life as an adult?

Greg Axtens

When I was 15 I left home because I couldn't get the help at home anymore. My mother couldn't cope with me at 15 because most of my bathing, my oldest brother helped me into the bath and he was going off to Uni at the time. My brother was a year older than me and he went off to Uni to study as a doctor, so that's why I went off to a place called Beach House which doesn't exist anymore.

There were 30 residents at Beach House and there were 10 residents at the stage where I came.

It was for older people, for geriatrics and then it became for people with disabilities.

Lisa

How did you feel at the age of 15 leaving your family home? The home that you've known since you were born? You still had younger siblings. Both your parents were at home, talk me through that experience.

Greg

I felt at the time I realized I was getting heavy for my mum. I knew it was not normal for children to leave at the time. It took me a while. It took me about a year to adjust to the rules of Beach House.

Lisa

Talk me through that- that that first year you said rules in terms of Beach house, is that correct? Were there certain expectations of you that you weren't used to?

Greg

I remember there was one woman who turned off my TV because I wasn't allowed to watch this particular show. You probably can guess. It was about a flat in Sydney. You can probably guess what it was called. It was very popular.

Lisa

Number 96. I guessed that Greg when you were saying that when you were leading up to that and you said the flat in Sydney straight away, I thought of Arnold. I thought of number 96.

I thought of Elaine, you know, my parents used to watch -well my mother used to watch number 96 and The Box. The Box was after number 96 and for listeners who aren't familiar with those shows, they were really, really raunchy. Weren't they Greg? There are much raunchier than television now and I used to creep into the breakfast bar and watch when I was a young teenager behind their backs, that's where I got my education.

Greg

Also people remember. It was the first show they had a gay character. Don Finlayson.

Lisa

Was the character named Arnold?

I thought there was a really camp character. I thought it was Arnold. Well, I could be wrong. Think you're the expert here?

Greg

No no. That was Dudley and I he was a shopkeeper.

Lisa

That's right, yeah, that's right. Yes, he was camp.

How often did you see your family during that time?

Did you ever get to go home?

Did they come to see you?

Every Christmas I would go home for two weeks. Until 1983 I think. In 83 it just got too much.

Lisa

To go home for the Christmas? For the two weeks. Did they visit you outside that though outside Christmas? Was there weekly visits with you.

Greg

About monthly

Lisa

So you went from living with your family daily to only seeing them once a month? Talk me through that.

That that sounds challenging to me. At the age of 15, and you know, Greg, no judgement on your parents as it's what that generation was told. But I just want to get to the bottom of how you felt as a 15 year old suddenly going from your parents place and living with your siblings on a daily basis to only seeing them once a month and not the whole family. Or was it just your parents who came to visit?

Greg

My Mum would bring the other siblings. And I thought it was just the way it was, but at the time.

Greg

That there were two older women who I remember who at the time I admired and I used to go to them for advice. A woman called Mrs Mooney and Miss Reid.

Lisa

And were they at the beach house? Tell me about them.

Greg

One was an immigrant from Scotland

And the other one was an immigrant from Ireland and they used to fight like cat and dog but at the same time they were best of friends. And they really were. And there was another man called Mr Pocket who used to be one of the most- he used to make the most brilliant place with tiles you can imagine?

And when I was 21 I got my first motorized chair and that was the beginning of me coming out of the closet.

Lisa

How do you equate those two things together? So at the age of 21, you got a motorized wheelchair, which I'm assuming opened up an entire world to you.

Where was Beach house by the way?

What suburb?

In Seaford

Lisa

So I'm assuming up until then, up until the motorized wheelchair Seaford was kind of your world, so the beach house and plus a little bit of Seaford was kind of where you stayed?

Greg

And during the day I used to go to children's spastic society.

There was training I had to do. It was a workshop from 1975 to 1986. I then went to Chelsea, then I went to a place called Southeast Industry.

Chelsea was all run by the Spastic Society.

And then I went to Stanford's industries and at South East Industries in about 1990.

In about 89 that's when I realised I first came out.

Lisa

And that coincided with your electric wheelchair. How long were you in the beach house for?

When what year did you leave there?

Greg

I left Beach House in 1990.

Lisa

And you went to where from there?

Greg

I went to Walkers Road and that's where I probably met you about the same time.

Lisa

That's going back a fair way. Now let me get to the bottom of the motorized wheelchair and the coming out. Talk me through how getting a motorized wheelchair opened up your world to the point where you decided that you were a gay man and what age were you?

Greg

I had just turned 29. I was able to go to the beach and watch the young boys jump off the pier. I thought I'm not attracted to girls. I'm attracted to boys.

Lisa

Tell me about how that felt for you. Was that something that was a positive thing given that you grew up, you were born in the very late 50s? Was that something that was a bit scary for you?

I knew at the time that I couldn't tell certain people because they may not understand that I am attracted to boys.

Lisa

Which people were they that you couldn't tell at the time? You felt you couldn't tell?

Greg

There were certain people at Beach house and there were certain people that I knew would understand.

Lisa

Were your two immigrant female friends part of your friendship group that you could tell something like that that you could out yourself too?

Greg

They had died and there was this woman who had just come out of the closet herself, and I knew I could trust her.

She really helped me.

Lisa

How did you know her?

Greg

She worked at Beach House.

Lisa

Was she the first person you told?

Greg

The first person I told was a woman that I still admire. Her name was Pam Gammet, and she got me in contact with an organization - The Victorian Aids Council. As one of the people, I really admire. One of the counsellors at the Victorian Aids Council whose name is Bill O'Loughlin.

Lisa

A very well known person in the community.

Greg

Yeah, and there was someone who I phoned weekly. Actually I phoned this person this morning. He's a bit of an icon in the LGBTI community. His name is Tex Perkins.

Lisa

I knew you were going to say Tex Perkins. Tex Perkins of course was at the VAC for 7000 years and of course when I used to work at Queer Film Festival it was also in the building of the VAC. I remember those days, yes. We shared offices with them for a long time. So Tex yes, certainly someone that we all

know in the Community and I can imagine knowing Tex and getting in touch with the VAC opened a whole other world for you. Talk me through that.

Greg

At the end of 89, the first gay bar I went to was in Commercial Road. The Exchange Hotel. That was the first drag show I ever went to was Terry's Back Yard. And for those people who can remember Terry's Back Yard was the place to go on a Friday night.

Lisa

So Greg, your world went from a non motorized wheelchair, pretty much cloistered in Seaford, you know, getting out a little bit to suddenly being at the Exchange Hotel. Mixing with the likes of Tex Mackenzie, did you come across other gay men with disabilities during your time out and about?

Greg

I only knew one other person.

His name was Dane Nelson and about three years later, I met another woman. Another disabled woman. Who is very well known in the LGBT community

Her name is Margaretta

Lisa

Coppolino yes.

Who I'm trying to get on this show, but we'll keep trying with Margarita of course, is very well known in the community as well.

You have very high falutin friends, Greg. Talk me through the realities of being out in gay bars and venues that you know, let's be honest, can be a little, maybe judgmental, a little bit attached to how we look. Talk me through how you felt about acceptance and being in those spaces.

Greg

People accepted me at The Exchange. But there's one bar which will remain nameless.

So Greg, do you have issues? Let's not name the venue. Do you still have issues with that venue?

Is it because it lacks accessibility or did you find there was a certain attitude?

Greg

A bit of both

Lisa

OK in terms of accessibility in terms of buildings.

Lisa

How much change have you seen over the last say 10 to 20 years?

Greg

There was one place I always wanted to go to. I realised I could never never, never, never get in.

And I'll name that venue. That venue was Club 80.

I realised no way in the world because there were too many stairs, wasn't there?

Lisa

Do you have issues with venues now or are things a lot better than they used to be?

Greg

It's a pity I can never get into Mollies.

I do think that the staff at Sircuit are pretty accepting.

Lisa

Because I guess you know that's something that people like me just take it for granted, you know we take it for granted that we can actually physically enter a venue or you know, we don't often think about the fact that there are many people in our community that can't actually get into the building, let alone feel welcome.

Lisa

Let me circle back to your family. Tell me about coming out to your family.

Greg

My mum took a while. When I first came out, she said the traditional thing. You can probably guess - it's a stage you're going through. And you'll grow out of it. But I never did.

Lisa

I'm glad you didn't Greg.

Greg

And my brother, my older brother, who's a doctor. He accepted me. And my sister, who also is a doctor, she accepted me, and my other two brothers it took a while for them to accept me, but they accept me.

Lisa

What's your relationship like with your family now?

Greg

My older brother, who's helping me to move to a place in Windsor and my sister. My youngest brother I phone once a week, but my older brother I phone nearly every day.

Lisa

And your parents are in a nursing home? How are they going? Can you visit them?

Can you speak to them on the phone?

Greg

I speak to my mum on the phone, but my dad is going deaf. My mum can't remember as much as she used to as she's in her 90s.

Lisa

Good, So what are your current living arrangements Greg?

Tell me about your where you live at the moment.

Greg

I live in Carrum. I've been there since 98 and those people who know me know that I don't spend much time there. I spend most of my time in this building. I come to this building about sometimes three times a week, sometimes four times a week. Before this building. I would spend time in Bourke Street. And I would spend. the other time in a place called Ross House.

Lisa

Oh yes, I know Ross house. So to clarify for listeners, the building that we're in right now is the Victorian Pride Centre, where Joy broadcasts from, we've got our studios here. And when Greg refers to Bourke St, he's talking about Council House I think it was called at the time and it was owned and still is owned by the City of Melbourne and it had a lot of community organisations like Joy, Melbourne Queer Film Festival, a whole bunch of arts organizations, Melbourne International Film Festival, Switchboard, lots of organizations.

However, now we're all in this beautiful building and I can understand why you come and visit here Greg, it's very accessible.

How do you get here, though? So you would get a train to where?

Greg

Balaclava and then sometimes I go up to St Kilda depending how I feel on the day.

Lisa

So how did COVID affect your life when you couldn't get out and about?

Greg

I got to know the people I live with very well.

Lisa

Ah, I love that. Do you live on your own?

Greg

I live with three others

It's a building that houses six people at the moment. In the time I've been there, two people have died.

And probably the main reason I'm still there, I thought from the time, when I was probably about 24. I thought to myself. Do I wanna spend the rest of my life like this?

But at the time I really didn't know how.

I realized I was upset about my mum. As I get older, I realized I'm not living for my mum anymore.

I'm living for me now.

Lisa

That's an incredible step to take, Greg and I guess we can kind of locate it back to that motorized wheelchair moment, but also the discovery of the VAC and the gueer community.

How do you get along with the people that you currently live with and what sort of care situation do you benefit from in your home?

Greg

Three staff

Lisa

Do they live in or are they kind of rotating staff?

Greg

Rotating staff. The days when I was staying there because of my pressure sores, I need time off my bottom.

There are days like all you want to do is stay in bed because of the weather anyway.

Who would wanna come out of a warm house into the city?

Lisa

Talk me through a day in the life of Greg. So talk me through, I don't know, a Wednesday from the moment you wake up to, the moment you go to sleep. Just an average Wednesday. What happens? Just give me give me an example of any day of a week.

Greg

These days about three times, four times a week I have somebody who helps me from the NDIS and she comes with me. But it's up to me If I need it or not.

Lisa

Because I see you out and about a lot and I rarely see you with a carer.

Greg

Most of the time. She comes, I do it. Send a direct part is as I get older I think only more.

But I don't think I'll ever be total dependent. I think I've got a good brain, and I think as most people who know me would agree I have a fantastic memory. If people who know me say one thing about me, it's that I've got a fantastic memory.

Lisa

Yeah, you have, You actually have got a very good memory.

Much better than mine because we've known each other for well over 20 years.

And you have often reminded me or ask me about things that I've had forgotten in my life.

So in terms of your level of care, Greg, what do you need the most help with?

Because your brain is so fit and healthy, but your body requires assistance, what's the most stark thing that you need help with?

Greg

Things like showering me in the morning and things like helping me to get dressed

Sometimes if I get bogged any where, which I don't get bogged very often, but I remember one night.

One night when I was coming home from The Exchange. If you know where The Exchange is, I was going up a famous street called Porter Steet. And I got bogged.

There was another guy who is also well known and whose name is also Greg.

Lisa

Yes, I know Greg

Greg

He helped me. At the time he worked at 55. Which most people my age, will know where 55 Porter Street was.

Lisa

So Greg, how important have queer organizations and events being in your life?

Greg

Pretty important, you would in the summer always see me at Midsummer, the Queer Film Festival, The Northside Bizarre and so and so.

Lisa

You've been to Mardi Gras in Sydney.

Talk me through that.

Greg

I've been to Mardi Gras three times.

I'm hoping to go to world pride next year.

The first time I went to Mardi Gras. I felt that was the first time I was a part of the disability LGBT community and I felt that was the first time I was alive. I could see other people who are LGBT in the street and I could say hi, I'm here
Lisa
Were you marching?
Who were you marching with?
Greg
A group that doesn't exist anymore, PFlag.
Lisa
Ah yes PFlag and the great Nan McGregor who we lost recently, who was an incredibly important part of Pflag.
So much love to her family.
We lost Nan only a few weeks ago you of course, remember Nan McGregor, wouldn't you, Greg?
Greg
Yeah, yes
I was here on Saturday at the memorial.
Lisa
So Greg, I'm going to finish up with you soon, but I want to know what are your future plans?
Greg
As I said. I want to move. And next week I'm having a meeting.
Lisa
So you want to move, so you're in the process of moving or you're applying to move?
Greg
I'm applying to move.
Lisa
Closer to town?
Greg
To Windsor.
Lisa

That's going to be much easier for you to get around to your favorite places.

So Greg, when you move, is it a similar facility to the one you're currently in so you have carers coming in? You live with other people with disabilities?

Greg

I will be with two other people.

Lisa

Well Greg, good luck with your move.

I can understand that you would want to be closer to the city because you're a busy bee and you're very social and I just want to say I love your constant presence at all of the queer events across Melbourne.

I love your resilience and I look forward to seeing you at the Pride Centre and any other event that comes up and thanks for coming to chat.

To me it's been an absolute pleasure Greg.

Greg

Yes.