

## **My Home, My Way: Podcast Transcript. Episode 4 – Whose Home is it Anyway?**

**Jake Briggs:** For us people with disability, living in our own home isn't something we expect to just happen...

**Sherryn West:** With my sister, living in her own home, she has that space and the freedom to live the life that she wants to live and to do it on her terms.

**Jake Briggs:** Often, we have to make it happen - by ourselves, or with our family and our allies.

**Sherryn West:** She's reclaimed her voice and her home, she's the boss and she's pretty good at telling everybody she's the boss and I'm happy that she's the boss.

**Jake Briggs:** I'm Jake Briggs and welcome to My Home, My way - A podcast about people with disability making their home, their own.

Living in a group home is often given as the only option for people with a disability - but that's not true.

It's not always what's best for us.

And group home living is not the typical way we make a home.

We don't say "hey I'd like to live with 5 strangers with the same diagnosis as me, that someone else chose, and have our home run by a service."

So what's the alternative?

My Home My Way has practical advice and stories of people with developmental disability, their allies and families, making a home on their terms.

... Coming up with unique support models that enable, even people with complex needs, to live in their own home.

By the way, this podcast is sensory-friendly, with a sensitive use of music, so you can listen comfortably.

**Jake Briggs:** What makes your home feel like yours? Is it a picture on the wall? Having family and friends over... Or just feeling relaxed when you close the bedroom door?

For me, it's when I first open the front door, and I look to my left, where an Aboriginal painting's hanging up. Painted by my mother, about my grandfather. A strong Wanamara Elder that went through the Stolen Generation, and showing his storylines, of where it all started to where he is now.

In this episode, you'll find out what Marisha likes to have on her walls , and how she made her home, her own.

**Jake Briggs:** Here's Marisha and her sister Sherryn, giving a conference presentation together.

[clapping]

**Sherryn West:** Ok, it's our turn. It's our turn. Stand up here.  
(whispering) Do you remember what you have to say? Say 'Good morning everyone'

**Marisha Targett:** Good morning.

**Sherryn West:** Good morning everyone. My name is.. My name is..

**Marisha Targett:** Marisha.

**Sherryn West:** And who am I?

**Marisha Targett:** My sister.

**Sherryn West:** : Your sister Sherryn, yep.

**Jake Briggs:** Marisha is the boss of her home.

**Sherryn West:** What we have done now, is to reclaim my sister and her voice. haven't we, Rish? It's your turn now.

**Marisha Targett:** I'm the boss.

**Sherryn West:** Yeah, you're the boss.

**Jake Briggs:** So how do you support someone with disability to be the boss of their home?

How can a house or a flat feel and look like a home, and not a workplace?

And how can you support your family member with disability to take on the roles of host to visitors, of neighbour ... or of the role of homeowner or housemate? Rather than the old, tired, devalued role of.... 'client'.

Well, Marisha wasn't always the boss of her home. Her sister Sherryn explains the small and big steps that got her there.

Here's Sherryn, at Marisha's home.

**Sherryn West:** We're sitting in Marisha's loungeroom. You'll see a lot of family photos. So Marisha is one of five children. So I'm the oldest and we have three other brothers. It's got a lot of her art. She's an artist and she had an exhibition at the Hope

Street cafe. And there's a rather large display of that sort of main piece of art, which is a nice centrepiece for her lounge room.

Downstairs, it's got two bedrooms. So one is the guest room. It's not a staff room. We changed that language around, you know, It's not 'a house', it's her home, and there's no 'staff room', it's a guest room.

**Sherryn West:** And then upstairs, there's a spare bedroom. We haven't quite worked out what we're doing with that.

We're thinking maybe her dressing boudoir. Because Marisha is a woman in her forties who loves to wear dresses and skirts. And she takes a lot of pride in how she looks and we thought that might be a way of her having all of her clothes, shoes, jewellery, hair clips, cause she has this amazing Afro... yeah if it's all out in this beautiful dressing room, then she can make her choices around what she's going to wear for the day.

Quite often after a big day, she'll love to come home and, um, probably change her dresses or skirt and, um, then sit on the couch and chill.

She has left all of her. Michael's all over the couch.

**Jake Briggs:** Marisha is a loyal Brisbane Lions fan, a passion she shares with her dad.

**Sherryn West:** My sister loves to carry a picture of Michael Voss. And he was the past Brisbane lions player and coach. And my father is a long time, I think even a founding supporter of the Brisbane bears now Lions.

He said he took Marisha to a practice match at Coorparoo once and she got to meet him and had a conversation with him. And I'm not sure if it's since then, but possibly? And then, yeah, she's always carried this picture.

She goes to OfficeWorks every Wednesday, her local store and they know her now. And she goes to the photocopier and prints various colours and sizes of Michael.

And it's great to see that you know, it's her home it's lived in. And she's created a home that she's comfortable in and got all of her favorite things in it.

One thing that's really important for her is that she continues to live in this townhouse because it's in the community where she grew up. She's lived here for so long, she's known. She's recognised. And I'm actually in the process of purchasing the property, so I've got that surety for her in terms of her living arrangements.

**Jake Briggs:** Marisha's townhouse really is her home.

**Sherryn West:** She's got places for all the things that are important to her - her art, her clothes, and her jewellery, and of course her Brisbane Lions memorabilia. And it's a place where she can just chill.

**Jake Briggs:** Marisha has lived here about 7 years. For the past two years, she's lived here alone. Before that Marisha had a flatmate, an old friend from school. Sherryn remembers the day Marisha moved out of home.

**Sherryn West:** She probably would have been thirties when she moved out of home. So it probably would have been 2012.

**Sherryn West:** So mum had chronic health issues. And so she obviously knew that she needed to set things up so that if something did happen to her, that Marisha was in a stable home environment in a home of her own.

It was almost like we were ready as a family for her to move out. All of her siblings had moved out, so she was the last child to be at home, but she was a young woman.

It was exciting. And I remember, I actually remember being emotional. I'm getting emotional now.

I remember driving there with mum. I said, "Why am I crying? You should be crying." But I think it was that whole recognition that as families we strive for having a family member live in a home of their own. And she'd done it. We'd reached that goal, that milestone.

And when she first move out of home, she moved into a unit. It was very small. It was with her school friend. It was over at Mount Gravatt so it was probably, you know, half an hour from mum and dad.

But if I look back at photos, she was very happy.

I think it was that I suppose, like when I think when I first moved out of home, it was exciting. You know, like you were independent, you had your own home. You were creating a space that was yours. I think there was that thrill.

**Jake Briggs:** Like for all of us, the first six months for Marisha were both exciting and challenging.

**Sherryn West:** And there were extra challenges too. A service provider was managing Marisha and her friend's home, and the location was far from the women's family homes.

Again, for my sister, it was different too, because she had all these different people coming in to support her. And I know initially that was really hard for her because it was a service provider. She didn't know who was coming into her home.

And then we went back and said, this isn't working. We wanted to self-manage because the two women are both very anxious because from one day to the next, they don't know who's coming in to support them.

At the same time, the location was just too far away for both families.

The two women moved here to Wynnum, which was great. Cause it was back in the local community where they'd both grown up and closer to both their families. That was certainly a good move for both of them and for the families as well, which was great.

**Jake Briggs:** So Marisha and her school friend were living in the townhouse, where Marisha lives now. They'd been housemates for 5 years. Sherryn sensed that things weren't going so well.

**Sherryn West:** My sister would come and stay at my place once every couple of weeks and she'd come for dinner on Sunday night and she wouldn't want to come home. And I was like, Nah, there's something wrong.

**Sherryn West:** I came and did some sleepovers and I thought, you know, I need to get, get, get some insight into what was happening, What was really noticeable was that my sister would pick up all of her Michaels and her favorite things and go off to her bedroom pretty much, right on 10 o'clock, if not before.

And her school friend would also go off to bed around 8, 8.30pm. And I know that my sister is a bit of a night owl and she likes to stay up. She would go to her room and close the door.

And what I worked out was happening was that the staff, because they were paid for a certain period of time and that 'awake shift' finished at 10 o'clock. The two women were being asked to go to their rooms at 10 o'clock. So that then the staff person could go upstairs to the staff room and go to sleep because their shift was technically over.

And so I made sure that when we had that change in her team that Marisha would just go to bed when she wanted to go to bed. It was a good reminder to staff that you're here to support my sister to live in her home and that if she chooses to stay awake till midnight or one o'clock or two o'clock, then she has the freedom to do that because this is her home.

And you can support her, and really, she doesn't need a lot of support. She just needs to know that there's someone here. So, you can go off to bed and go to sleep. And if Marisha needs you, she'll come and get you.

**Jake Briggs:** Marisha's flatmate Cindy moved out suddenly. A year on, Sherryn thinks it had some surprising silver linings.

**Sherryn West:** One thing I did when my sister's friend moved out was we had a bit of a cleanup and it, I think combination of my sister's friend moving out and me coming and sort of helping my sister to reclaim her home, there was all that change.

And I know my sister, she needs time for those big changes.

I noticed there was a lot of second-hand things in her home. There was this real culture of secondhand shopping. I'm not against that, but it, for me, it devalues my

sister. I want to see her things in her home that are new, that are nice, that are matching.

So I made sure that, you know, all of her linens, all the towels were the same colour and you know, the tea towels are matching and the crockery is, you know, all the same and there's not this mix match of different plates and cups.

I guess sometimes I make assumptions on what my sister will like.

And so I remember, taking my sister shopping and we were getting, I think it might've been the colour of the curtains. And I was asking her if she liked this colour and it was just this flat out, "No!" It was a good reminder. I need to check in with my sister because it is her home.

It's not what I think she will like, it's what she likes.

So it's been fun to support her to do that. And we're both a bit excited about when the property becomes ours and we don't live in this rental arrangement anymore where we can't technically do anything.

**Sherryn West:** But I'll have to remember that, you know, this is my sister's home and I need to check with her what she wants, because her tastes are different to mine.

**Jake Briggs:** Since Marisha has been living alone, her family has also supported her to work on her communication.

**Sherryn West:** The difference, now that she's living alone is I think quite significant for when she was here and sharing her home with her friend.

So Marisha is a woman who has limited speech. Well, she has a voice, but it's a high-pitched vocal box and sometimes it's difficult for her to formulate, say like S sounds. We're doing a lot of work with supporting her to enhance her communication.

She was quite often either misunderstood or ignored, because her friend that she lived with had really good speech. And so her needs were often overshadowed because the other woman was able to clearly articulate what she wanted.

It was a real concern for me before mum died... cause you know, parents often speak for their son or daughter, that when she did die, that Marisha wouldn't be able to clearly state what her needs and wants are. So we've been able to work a lot on her speech and supporting her to do that.

And really noticed a big difference in when her friend moved out to now. I think it was great that they lived together for the start.

Now I've seen my sister really evolve and really claim her voice and her home and who she is, because she's got that physical space to do that as well.

**Jake Briggs:** Other things that make Marisha's home feel like hers are how staff come into her home, who has keys and Marisha knowing who's coming when.

**Sherryn West:** When there's that changeover of staff and people come in, that you don't just come in. You knock on the door and ask, you know, "Hi Marisha" and she'll let you know that you're welcome to come in.

And also - keys. I know the previous staff group used to all have a key to her home, Well, it's like, no, this is Marisha's home. So now only Marisha has a key. I'm the only other person that has a key and that's really just for letting tradesmen in, if she's out, and for emergencies.

And I think just the whole language around it being her home. It's been good to change that whole dynamic around that.

**Jake Briggs:** The sense of it being Marisha's home has grown in other ways too, as she takes on other responsibilities.

**Sherryn West:** So my sister I suppose has had that life of privilege where she's had a family member do a lot of things for her in the past. And now that she has the space in her own home to do her own, daily tasks, she's really embraced that.

**Sherryn West:** She goes and does her own grocery shopping. When she was living with her school friend that was often done by a staff member. And Marisha I guess her diet and her eating habits were restricted because her friend was always on a diet. So now my sister's able to have, you know, the chocolate and the ice cream and the Chicken Crimpy biscuits that she loves in the cupboard so that she can go and get them whenever she wants to.

She does like to cook. She doesn't like to do her gardening. She will hang out her washing. Yeah, she does need assistance with most things around her home, but she'll certainly give it a go.

**Jake Briggs:** It's not only family members that can help build someone's sense of home. Sherryn points how support workers can assist a person with disability to take on the role of host of a dinner at their home.

**Sherryn West:** As a family member, we hardly ever got dinner invitations. I sort of try and guide and lead her support team now. It's really interesting to try and educate and teach them that, you know, I need you to support my sister to develop relationships with her family. And that might mean a dinner invitation.

And I guess that was hard at first to recognise that you had to actually ask someone to ask you to do that. Like, I obviously had this expectation that a worker would know that my sister would want to have someone for dinner.

Whereas actually I have to actually ask the staff to say, well, look, I want a dinner invitation and then it will happen. The realisation for that was quite interesting for me, Because you sort of have this expectation that these natural things that I take for granted don't happen for my sister.

I have to actually make them happen.

Like, well, if you do it as a person, why can't you support my sister to do it?

If it's a natural thing that we do as family members, wouldn't you think as being a supporter to my sister that you might want to ask her, does she want to have a family member over for dinner? Or, it's other things like I've given her team a list of family birthdays and anniversary dates, and it's only might be a particular worker that might remember that.

Or I might ask the team to support my sister to create a birthday calendar so that she knows that, you know, she's got to ring her niece Elsie on her birthday or organise to have a present or organise for her to come for coffee or cake or something. But it's that, the constant reminder, I think that that's your role to do that.

**Jake Briggs:** Marisha being in her own home, by herself, has meant that she's connected and well known in her community.

**Sherryn West:** Recently she had the dinner invitation from the neighbour, which was great because it was that whole recognition of all that you work towards with building those informal networks for your family member.

**Sherryn West:** You know, it might've taken six years for that dinner invitation, but it is a dinner invitation and it's opened up that opportunity for her to build those relationships with people that she lives next to.

It's been really important to ensure that my sister's visible, visible in her home and where she lives, but also out in the community.

We know that people keep people safe.

**Jake Briggs:** So what does Sherryn wish she knew, before she started supporting Marisha to live in her own home?

**Sherryn West:** I think the biggest thing is trust. Trusting workers. I'm a person who trusts people and trust has been broken. And I think it's really hard to build that trust back up again.

Families share that particular vulnerability of their family member and their family to workers. Sometimes that gets taken for granted. There's an energy that gets zapped from families each time that you have that change in staff.

I've learnt that you just have to be upfront and honest from the beginning. You have to act quickly if there is that threat to that trust, otherwise it becomes toxic. For my sister, you know, I think there's, there's, an increased vulnerability because of her, her limitations with her being able to express that. But we're doing a lot of work on that now with her.



**Jake Briggs:** Sherryn is also planning for the future, for when she's not around. Succession planning is so important, we've got a whole episode about it - Episode 8.

Here's Sherryn, speaking at that conference presentation you heard at the beginning.

**Sherryn West:** Think about succession. So, you know, the death of mum has really highlighted that for me now too. Because I'm conscious that I don't have any children. Our brothers are useless in terms of...  
[crowd laughing]

Aren't they? They're not gonna be any good at picking up the mantle. So now we've got to look at you know, whether there's a niece or something... yeah, who's going to pick up the baton now, to carry that on?

**Jake Briggs:** Living on her own has made a huge difference to Marisha's life.

**Sherryn West:** I think the difference of my sister living in her own home... she is the owner of her life and what she does.

With her being able to live in her home where she's comfortable, where she knows she can be vulnerable, that's really important.

With my sister, living in her own home, she has that space and the freedom to live the life that she wants to live and to do it on her terms.

**Sherryn West:** She's very good at saying, 'She's the boss'. So now that she's reclaimed her voice and her home. She's the boss and she's pretty good at telling everybody, 'She's the boss' and I'm happy that she's the boss.

**Jake Briggs:** That was Sherryn West and her sister Marisha Targett.

Living with another person with a disability doesn't always mean that people are compatible and can mean less control.

It's important for the person to claim their voice over their tastes and preferences in regard to their home, rather than have others make choices for them.

Support workers have an important role to play in building trust, tuning into what genuinely makes a home for each person and fostering old and new relationships.

What safeguards people is people - for people with disability to be visible, well known and valued within their local community for their contribution.

**Sherryn West:** : And you gotta say, "My home my way."

**Marisha Targett:** My home my way.

**Sherryn West:** Yep, my home my way.

**Jake Briggs:** In the next episode of My Home, My Way, you'll hear about unique models of support, paid and unpaid. To help you live and stay living in your own place.

**Linda Hughes:** so a circle of support, it's generally people who are friends and family of Jacob's who come together to sort of brainstorm to think and help plan and help Jacob craft his future...

**Jake Briggs:** You can find the Show Notes for this episode, with the main points, and a transcript on the My Home My Way website.

The My Home My Way website also has lots of resources, stories and tips for you to get your own place on your terms, or to support someone else to.

Type My Home My Way into a search engine, or go to [www.myhomemyway.com.au](http://www.myhomemyway.com.au)

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Thanks for listening.