Purple Orange Podcast, Season 2, Episode 1:

Freedom means a good life

**SPEAKERS**

# Belle Owen (host), Carey Scheer (interviewer and narrator), Tim Hanley (guest), Sandy Hanley (Tim’s mother), Dave (Tim’s support worker)

**Belle Owen** 00:00

Hello, I'm Belle Owen, and you're listening to the Purple Orange podcast. Today’s episode is a special edition. It was made by Purple Orange for the My Home My Way Podcast, that is a podcast series where you'll hear alternatives to the traditional disability group home.

I'm a proud disabled woman. I cannot imagine being told I have no choice over who I live with, or how I plan my day. And yet for many disabled people, that's the reality of their life in a group home. Everyone should have choice and control over how they live, where they live, and who they live with. This episode is about the profound personal transformation of one young man who had those choices taken away from him, but then got them back.

Just a heads up, this episode does contain brief descriptions of expressions of distress, which includes self-harm. If you aren't able to listen to that, it is okay to skip. But know that if you can hang in through the rough time, you'll be rewarded with a remarkable story of empowerment.

**Carey Scheer** 01:01

Tim Hanley lived in a group home for about a decade. When he first moved into a home on his own, he told his mom Sandy, he wanted a pet rabbit.

# Sandy Hanley 01:11

And so we went together up to a farm and picked out a rabbit.

# Tim Hanely 01:19

She was a little baby then. She knocked my feet over and asked me, "Do you want me in your life?" I'm a lot happier now, and I got a friend in the house.

# Carey Scheer 01:36

Tim named his rabbit Lily.

# Sandy Hanley 01:40

He's achieved what he wanted to achieve being his own pet owner. That was big for him.

# Carey Scheer 01:47

Because yeah, because in the group home, there'll be no opportunity for him to do that?

# Sandy Hanley 01:50

No, we asked about him getting a pet and it was quickly, "No." It would be too hard for one person to have a pet and not another person to have a pet. Therefore there's a blanket rule no pets.

# Carey Scheer 02:06

Is it hard for you to talk about the time when you lived in the group home?

# Tim Hanley 02:13

It's really sad. I have no friends there. And can't have a pet- It's the rules. And I can't have- I can't go out by myself. I stay in my room all day. Upset, feel down, just by myself.

# Carey Scheer 02:42

During the day, the group home would try to get Tim out of his room, but not to a place of his choosing.

# Sandy Hanley 02:49

No, they actually weren't sending him off to another day options where it was huge number of other people with disabilities and there was an array of things, it was just awful because he hated it. And I remember them saying, trying to get him out to go to day options, telling him that the house closed between 10am and 3pm. So there wouldn't be anybody in the accommodation house to look after him, so he had to go. So that's when a lot of running away started. I would have the house manager ring up sometimes and say that he'd left, he'd abscond and they didn't know where he was. I saw him do some self-harm.

# Carey Scheer 03:33

The Tim I've met today, I can't imagine him doing that. It's like Sandy is talking about a complete other person. So I asked him, "What made him feel he had to do those things?"

# Tim Hanely 03:45

Because I got no choices with going out together. I don't want to go in with other people in the car. People fight in the van, and hit and fight and not get along with each other. Feel not safe.

# Sandy Hanley 04:13

So I think, almost like he was in prison, you know, those kinds of behaviours where you've just had all your rights taken away, you've had to fight for every little thing. Just having the right to, to go out for a walk, to having the right to walk out the front door and sit in some sunshine.

# Carey Scheer 04:40

This is an issue that many people who have lived in group homes talk about. That they have no choices. That they are not free to live their life the way the want, where they want and with whom they want. Make no mistake. Acts of self-harm are acts of protest which many people, disabled or not, reach for when their rights are denied.

# Sandy Hanley 05:05

You know, having the right to say, "Can I go to mom's house?", without it turning into this huge thing where, "Oh we going out at 11. So she would need to get here before then. And we won't be back till four because we've got our own activities that we're doing so she can't bring you back until after four." So the simplest little decisions turn out to be a major- a major event, where it just I think Tim felt sometimes it's just too hard. I'll just stay in my room. I'll just stay asleep. Wait for the next meal to arrive.

# Carey Scheer 05:47

Living for the next meal, that's not good for anybody. But especially for Tim. He has Prader Willi Syndrome. Everyone in the group home did. And one of the notable features of Prader Willi Syndrome is a constant feeling of hunger. It often leads to excessive overeating. The group home managed this by keeping residents totally away from food until mealtime.

[doorbell rings. Door opens]

# Tim Hanely 06:18

This is Dave.

**Dave** 06:18

Hello, how are you?.

# Carey Scheer 06:20

Nice to meet you.

# Carey Scheer 06:20

I spent a couple days hanging with Tim to get a feel for what his life is like. He took me to the community garden where he grows his own vegetables and regularly catches up with his fellow gardeners for tea. He showed me where he exercises in the park nearby. We walked along the beach to his favourite restaurant, played games with his three-year-old niece when she came to visit, and then as is his weekly ritual, he cooked dinner for his parents on Thursday night with the help of his support worker Dave.

# Tim Hanley 06:53

So hard to make sushi. I need to learn and learn and learn.

# Dave 06:57

Well you know some people spend years just learning how to cook the rice, did you know that?

# Tim Hanley 07:01

I know.

# Carey Scheer 07:05

Tim, when you were in the group home was the food locked up?

# Tim Hanley 07:08

Yes, everything locked up and it's not that great when food's locked up and I can't cook and staff just cook for me and make my lunch. I want to help out because I get lazy in a day, and I might get bored. I might do- just sit and do nothing and that is not okay.

# Carey Scheer 07:33

Tim's mom, Sandy said she tried to get the group home to be more flexible around their strict locked food policy.

# Sandy Hanley 07:40

What Prader Willi Syndrome means for Tim, is that he does love food. He is quite obsessed with food. But he actually loves the whole aspect of it. He loves shopping bags, writing a shopping list, going shopping, collecting things in the trolley, going to the checkout, packing them in the bags, taking them home, unpacking, putting the bags back in the car, helping prepare a meal and dishes. He loves doing dishes and putting dishes away. But I couldn't convince the group home that you're actually taking all of those things away from him, locking him out of the kitchen and just providing him with a meal on his tray.

# Dave 08:23

So, what are you doing Tim?

# Tim Hanley 08:24

I'm peeling the carrot with a grater. And that will go in the sushi.

**Dave** 08:34

Okay, and so what I'm doing is I'm going to cut the cucumber.

# Tim Hanley 08:37

Yeah.

**Dave** 08:38

This is really cool because we're not, we're not working from our strengths here. We're actually working from our weaknesses. So this is really I guess what empowerment looks like.

# Carey Scheer 08:51

So is it challenging for you right now to not eat the food as you're cooking?

# Tim Hanley 08:57

A bit, but I cope really well because it's about trusting me to not eat the food.

# Dave 09:06

We've had a couple of times when bits have disappeared. But you know, that's recognising me, you know, I need to recognise where the safety net needs to be. Because your health is really important, isn't it?

# Tim Hanley 09:23

Yeah.

# Carey Scheer 09:25

Tim appears to be fit and healthy, whatever safety nets they're putting into place seem to be working.

# Tim Hanley 09:31

I'm putting the tuna in the sushi.

# Dave 09:34

Spicy Tuna.

# Tim Hanley 09:35

Spicy Sushi.

# Dave 09:39

So us doing this, Tim gets a lot of gratification out of knowing that he is doing something good for mum and for dad.

# Tim Hanley 09:47

Yes. Because they say, "Mmm Mmm, that taste's nice. Thank you Tim for cook for us." because they have to work hard. And so I help them to make dinner, so we don't miss out.

# Carey Scheer 10:03

So the amount of joy that that brings helps you [to] stay disciplined.

# Tim Hanley 10:07

Yes.

# Carey Scheer 10:09

When Tim first moved into the group home, his family was at a breaking point. Tim has high support needs, his parents needed more help, and they weren't getting it. They also have two younger children who are still at school at the time. And they also were struggling. Basically, no one was getting their needs met. Sandy thought the group home with dedicated support staff would be a place that Tim would be better off, happier, even.

# Sandy Hanley 10:38

I was actually expecting them to do a better job than me because they- these people come on shift. And they're not there 24/7. And they have a shift where, I was presuming they were going to come up and come in and, and really care and look after and do a better job than what I was doing. I realise how naive I am now. I'm going to forgive myself for that.

# Carey Scheer 11:13

In the group home, the staff are employed to look after everybody. And that makes it hard to support individuals.

# Sandy Hanley 11:20

There was certainly no talk about ever finding a staff member that, you know, had similar interests to any of the people that they were supporting. I don't know if babysitting is the right word, but you know, they were just really there making sure that no one was coming to too much harm. And that they were getting fed. And that's, that's not what support work is about.

# Carey Scheer 11:49

Once Tim was out of the group home, Sandy made sure Tim had the power to choose support workers he liked. It's an ongoing conversation.

# Sandy Hanley 11:59

We can try them for a while. And if you don't think that that support worker is going to be good for you, you're allowed to tell me. You're allowed to tell me and it won't matter. They will find somebody else to support and we'll find the right person for you. That's been great for Tim. He's got a say. He's been listened to. He's got some control over who's with him. And he knows all of his support workers names, which is something that often didn't happen in a group home.

# Carey Scheer 12:32

Is he a good support worker?

# Tim Hanley 12:34

Yes, definitely.

# Carey Scheer 12:36

What do you like about him?

# Tim Hanley 12:37

Well he's very nice, kind. Have fun together and cook.

# Carey Scheer 12:48

What do you like about your job?

# Dave 12:50

Ah, seeing people shine. I think that's it. You know, when you see people accomplish things for themselves, hand over the steering wheel and let them sort of steer and direct their own sort of thoughts and decisions then and see them shine in that space, I think that's, that's really special. Is it looking good buddy?

# Tim Hanley 13:14

It is looking good yes.

# Dave 13:18

You ripper, look at that.

# Tim Hanley 13:19

Nice and colourful. It's just like a rainbow.

# Carey Scheer 13:26

When Tim lived in the group home, Sandy would bring him home to stay one weekend a month. He would pace around, seem agitated, and when Sunday came around, he'd obsess about being back to the group home in time for his afternoon tea.

# Sandy Hanley 13:41

I used to think he was wanted to go back to the house because of that behaviour. But I realise now he knew that he, he was going to go back to the house. So just probably the quicker that he got back there, the better. It was almost like if he enjoyed himself too much, it was sad for him.

# Carey Scheer 14:03

Sandy realised this during the pandemic, she brought him home, because if the world was going to lock down, she wasn't going to be separated from her son. And it was then that his behaviour started to calm down.

# Sandy Hanley 14:15

He was actually really content just being at home, knowing that while the pandemic was around, I wasn't going to send him back. He was going to live with us. And I actually said to Tim, do you want to stay living with mom and dad? And he just said, "Yes, yes, mum. Yes mum. Yes, mum." And it was like, it was like a whole heap of stuff had been released from him. This wasn't being held over him that at some point he was going to return.

# Carey Scheer 14:54

During the pandemic, the NDIS approved a temporary change of plan that allowed Tim the funding he needed for individual support work during the day. This meant his parents could keep on working. But once the pandemic ended, Sandy says this extra funding stopped. Sandy put forward a case to keep the funding going. But it was denied.

# Sandy Hanley 15:16

They could see that there'd been a huge improvement with Tim and really felt that he could go back living with others. There was no reason why he would need to stay independent, when a lot of his behaviours of concern was seen to be improving.

# Carey Scheer 15:35

Could you have sent him back to a group home?

# Sandy Hanley 15:37

Never could never go back. Never.

# Carey Scheer 15:42

Sandy appealed that NDIS decision. Her appeal was also denied.

# Sandy Hanley 15:48

They said this is all we are going to give you so you know, if you decide not to send Tim to a group home, that's your choice. You just have to manage what you've got- the money that you've got, because I'm saying, Well, I can't have him during the day I work.

# Carey Scheer 16:02

The next step was the tribunal. In the meantime, the family did everything they could to scrape by and cover the cost of Tim's support. And then after two years, they finally won the support hours that they were seeking.

# Sandy Hanley 16:18

I think when you're young, you're naive. And you just think that everything will be alright. And you learn that as you get older, it's only okay, all right, because of the work that you've put into it. It doesn't naturally fall into place.

# Carey Scheer 16:36

With Tim's support hours now being covered by the NDIS, his parents have been able to rent him a place next door. Tim can pop over to his parents’ house anytime he likes. But he loves the independence of living on his own.

# Sandy Hanley 16:50

Ten years ago, I wouldn't have recognised the Tim that I see now. Any of his behaviours that were challenging have just about disappeared. He is the happiest young man in the whole world. And he will tell you that.

# Carey Scheer 17:13

What has living in a home of your own- how has it changed your life?

# Tim Hanley 17:19

I'm a lot happier. I am very a lot happy. I am behaving every day. I got a niece. I got a rabbit, named Lily and I've got freedom.

# Carey Scheer 17:36

Freedom?

# Tim Hanley 17:38

Have freedom mean live a good life.

# Belle Owen 17:45

We'd like to thank Tim Hanley for sharing his story and powerful message. Everyone should have the choice and control over how they live, where they live and who they live with. To hear other stories about home or find resources and tips for you to get your own place on your terms or to support someone else to, head to the My Home, My Way website, [www.myhomemyway.com.au](http://www.myhomemyway.com.au).

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