Luana (00:00):

I think one of the biggest things and the hardest things for carers is the isolation. And I would go to playgroup and all the other parents would be there and their children would be involved, and Ollie would just want to go to the corner and play with his toys and play just with me one-on-one and wouldn't connect. So a lot of the isolation in that I didn't get to really connect or have those moments where my kids were playing and I could just sit and connect with other parents. I would be always with him. And in the end of the day, it was kind of like, it's much easier to just be at home and be one-on-one with you because I feel so alone coming to this and being on my own anyway.

Peter (00:49):

Hello, I'm Peter Gee. Did you know that one in six Tasmanians are a carer? A carer provides unpaid support to a family member, friend, or neighbor with disability, mental ill health, chronic or life-limiting illness, or who are frail or aged, or have alcohol or drug dependence. As you'll hear, their stories can be challenging and heartbreaking, but also inspiring and heartwarming.

(01:14):

This one in six podcast is presented by Care2Serve. Part of the Carers Tasmania Group. Care2Serve is the Tasmanian provider of Carer Gateway, an Australian government program offering free services and support for family and friend carers.

Luana (01:36):

Hi, my name's Luana. I'm 44 years old from Kingston, Tasmania, and I care for my amazing son, Ollie.

Peter (01:43):

Luana, thanks for inviting us into your sunny Kingston home.

Luana (01:47):

Thank you for coming. It's great to have you here.

Peter (01:50):

Now, for people listening to this podcast in Tasmania, they might recognise you as the curly-headed one on the Care2Serve ads or from the back of a bus.

Luana (02:01):

They may indeed, although I might be a little bit horrified about that.

Peter (02:05):

You?

Luana (02:06):

Yes.

Peter (02:07):

Have you been recognised?

Luana (02:08):

I have been. Yes, indeed. Yep.

Peter (02:11):

But you've been an advocate for caring?

Luana (02:14):

Yes.

Peter (02:15):

For how long?

Luana (02:16):

For, I would say six years. My son was diagnosed with autism at two years old. So yeah, it's been a learning journey.

Peter (02:24):

Tell us about your now eight-year-old son, Ollie.

Luana (02:27):

Yeah. My son Ollie is the most wonderful human being I know. He's eight years old, and he is a joy and delight. He's the most caring, kind... Ah. Just... yeah. I'm sorry. I could talk forever about my son. I love him. He's my bestie. He's autistic, but we also have some co-diagnoses with that, so-

Peter (02:52):

No form of autism is exactly the same?

Luana (02:56):

No. No, not at all. So I think my son really struggles a lot with the social side of things, in saying that he's the most social person you'll ever come across.

Peter (03:07):

When he goes up to people uninvited and....

Luana (03:10):

Oh my, oh, no, not uninvited. You probably wouldn't even realise he has autism. He's just an awesome kid. It's just more that when it's with peers, in school settings, in playgrounds, play dates, it's just trying to read the unwritten or the unsaid things. The unwritten-

Peter (03:29):

He doesn't get the cues?

Luana (03:30):

No, he doesn't get the cues, and he can be quite intense because he's just so wanting to connect. And it's just really hard as a parent to see. He has so many great skills, but without support there, without adult support there or another child who understands that, it's just heartbreaking when play isn't successful or when he's left out of things.

(03:56):

Yeah. So yeah, he's amazing, and he tries so hard. And I don't want him to grow up thinking that he has to change. He's made perfect just the way he is. And I think that's my passion in that he doesn't have to change. society does. And I'm very, very, very passionate about that, especially in the education system.

(04:20):

I think a lot of therapy is around our kids being trained to act neurotypical, normal, whatever people's idea of normal is. And I am just like, "No, things need to change. We need to change education, we need to change workforces." Yeah. I talk about Ollie's autism openly. I want him to grow up proud of it. His brain can do things that mine can't. And he's not wrong, yeah. So...

(05:03):

Since he was born, he had severe reflux, and that was just... So he would cry for five, six hours at a time. So just very sensitive to everything around him. And then in the very early years, it was like, "Oh, he's very quirky." And my first child, it was just Ollie. It was my child, and nothing to compare it with.

(05:27):

And so yeah, it was at the age of two that it started to be earmarked of, "Okay, he might be autistic." And I think it was just... Yeah, it's hard 'cause as a parent, he was just Ollie. But yeah, the therapists and the healthcare nurses were like, "Ah, okay, he is a little bit quirky." There wasn't any huge delays. He did not speak a lot until he was two. But then when he was two, he just started with full-on sentences and straight off. So yeah, it was just that quirkiness, just those little things of sensitivity to labels and clothes or... A lot of other things were going on too. His ability to be able to swallow and drink water and different textures and things like that. So it was just very subtle things in the beginning.

(06:18):

For Ollie, a lot of the things really started to show more when we started playgroups, when we started school. That's when a lot of these things came to the surface.

Peter (06:31):

And what were the difficulties that you encountered in raising him?

Luana (06:37):

I am a sole parent, so it's me 24/7. Yeah, look, I think one of the biggest things and the hardest things for carers is the isolation. And I would go to playgroup and all the other parents would be there and their children would be involved. And Ollie would just want to go to the corner and play with his toys and play just with me one-on-one and wouldn't connect. So a lot of the isolation in that I didn't get to really connect or have those moments where my kids were playing and I could just sit and connect with other parents. I would be always with him. And in the end of the day, it was kind like, "It's much easier to just be at home and be one-on-one with you" because I feel so alone coming to this and being on my own anyway. Yeah, so-

Peter (07:26):

Do you think that's a common thing that you-

Luana (07:27):

Absolutely.

Peter (07:28):

... retreat into your own? You could if you wanted to?

Luana (07:31):

I don't think it's a matter of retreating into your own. It's more just the lack of understanding from other people. And I don't know, like I said, like you said before, everyone's autistic journey is very different.

Peter (07:51):

But there's a time when he has to go to school, I guess.

Luana (07:53):

There is.

Peter (07:55):

You can't be educating him, I suppose.

Luana (07:58):

No.

Peter (07:59):

You're not qualified.

Luana (08:00):

Oh look, I would homeschool him in an instant, in an instant, because it would take away so much anxiety for him, so many of the challenges. And I never want him to feel less than or wrong or different. But the thing is, if I did that, I would never get a minute, ever, to myself. I couldn't do it 24/7 and still exist as a human being.

Peter (08:24):

Well, you got to make-

Luana (08:24):

Mentally for my health either

Peter (08:24):

You got to make ends meet too

Luana (08:27):

Yeah, I do. And that's been also a challenge, especially in Tasmania, because there's huge lacks of therapists. And so when you get into a therapist, you can't get Tuesday, nine o'clock every week. You get what you can take and-

Peter (08:43):

It's hard to hold down a job while you have been-

Luana (08:46):

Well, exactly. And we've been waiting since December for an OT again. So it's kind of like, how employable are you? Because are you going to then not get your children to this therapy at the cost of you being out of work? And I can't do that at the cost of him missing out on what he needs and really good therapy. So yeah, it is hard to do a job. And this year I had a couple of scholarships, and I started uni full-time. And it was just not achievable to be able to do; be a parent first and foremost, a full-time student, and a carer, I just couldn't do it. And you can say, "Do part-time uni," but then once your child's eight, if it's part-time, with the extra time that you're getting, you have to be looking for work or doing work, so you don't get the extra time to study anyway. So it's actually, this year's been a really, really tricky year in terms of me wanting to do something for myself but not being able to do it at the cost of him. And yeah, it's not easy.

Peter (09:51):

He's at school now.

Luana (09:53):

He is.

Peter (09:54):

How is he coping without you?

Luana (09:57):

Yeah. Oh look, he's a very flexible person. He's at his best when he is with me. But yeah, look, he comes home, a lot of the time, very lonely. His day is made by whether playtime is successful or not. If he's had successful play, that's a good day for him. And then he probably requires less support in the classroom as well, because that's who he is, that connection.

(10:23):

So he's fine without me. But in his early years of education, I would have him, we were at a different school, and I would have him come home. And he would cry so deeply, for up to two hours, just saying, "Mama, I would do anything just to have one person who cared for me at school." And-

Peter (10:48):

Is this amongst his classmates or someone in authority, a teacher?

Luana (10:55):

Look, I think both, both. I think what I've learned in the schooling journey is how important it is to have a principal who truly, truly understands special needs and truly wants inclusivity. I think there's a lot of attention on resilience, but my number one thing is a child can't learn to be resilient if they don't feel safe.

(11:18):

I've never been about pushing education. My son's a smart kid, he will learn. But my number one thing is his mental health, is him being happy to go to school, him coming home, not broken. So school's been hard, a really hard journey. And I think the other thing that a lot of carers probably will relate to is when you are in a school and it is tricky, or education setting and it's tricky, and you have to be the parent who advocates for your child, I think the hardest thing for me in the first school my son was at was the way that I was seen as that parent, just for advocating for the small things like my son's ability to use the disabled toilet. For three years, I had to battle that and be seen as that parent. I got to the point where I couldn't even go up that road without almost having a panic attack to pick him up. Yeah.

Peter (12:12):

So did they think having the disabled toilet was, that's job done? We don't need trained staff to actually help those that need it?

Luana (12:19):

No, he wasn't allowed to use the disabled toilet.

Peter (12:22):

Really?

Luana (12:22):

Yeah, because then he'd be seen as different. He has a lot of sensitivity to hand dryers, and there was one of those in the airports; the hand dryers where you put your hands down and-

Peter (12:32):

And he thought he wasn't going to get his hands back.

Luana (12:34):

Well, it's just the sound. The sound physically hurt his ears. It's like going into a toilet and being afraid of Huntsman's and there's a Huntsman there every day and they're saying, "Well, just take someone to stand guard over the Huntsman."

Peter (12:48):

That's a spider for anyone who's listening that doesn't have those big fury friends that we love in Australia.

Luana (12:52):

Just say, "Oh, bring someone with you to the toilet, and they can keep an eye on that and make sure it doesn't jump on you." But you've still got to go to the toilet with that Huntsman next to you like it's... Anyway, it was... I think, yeah, one of my biggest things is find a principal and the learning support staff who truly, truly understand special needs and are that safe place for your child that, when things are not working, they have a safe person in the school that can be held in that space and just nurtured through that.

Peter (13:27):

So did you hunt around to find the school where he is now that has those sort of people?

Luana (13:33):

We absolutely did. I just realised that no, I can't put my child through this anymore, or myself actually. It really affected me as a carer, as a parent. And we found, when we first moved to this school, the most amazing special needs coordinator. Just from the minute we walked in, I had said, "Oh, my son has dyspraxia" as well. I mentioned before that there's a few coexisting diagnoses along with autism. Dyspraxia is one of them.

Peter (14:06):

Could you explain that?

Luana (14:06):

Yeah, that is your brain's connection with your body. So if you're learning a new skill, someone could just show a kid and say, "Okay, you throw a cricket ball like this," and the other kids would see and go, "Okay, that's what I have to do." For Ollie, you really need someone who's going to hold that hand and show him and help him move that arm in that direction so that his brain connects with his body. So it means he falls a lot. Kids do, of course, but a lot more for someone with dyspraxia. So yeah, so it was just that matter of that first meeting. And I said, "Oh yeah, Ollie's got dyspraxia." And this lady turned to me and she said, "Oh yeah, I noticed all the cuts and bruises on his knees." And I'm like, "You are my person, you get this."

(14:53):

The fact that she knew what dyspraxia was and the fact that she'd even noticed that about my child. And that was just the most amazing moment in finding this new school. She's no longer at the school now. But yeah, it was a pivotal moment of choosing that school for him. And that first year while she was there, I can't tell you. It was the first time I felt like I could breathe while he's at school because I'm like, "He's got a safe person. He's got someone who's going to hold him when things fall apart."

Peter (15:25):

Is a regular school the right place for someone with special needs?

Luana (15:30):

Yeah.

Peter (15:30):

A disability?

Luana (15:30):

That's a great question. I am all for inclusivity. I am. But I am more for trained teachers and teachers assistants and learning support staff that truly understand and can support our neurodiverse children.

So actually, it's funny you ask, but I'm actually in the process of looking at a school in Melbourne that has started an autistic school. And that's a huge thing. That means me-

Peter (16:03):

A school that's starting an autistic school? So this would be on-

Luana (16:06):

Within their campus.

Peter (16:06):

Really?

Luana (16:07):

Yeah, within their campus. So it's only started this year, it's only 10 students. But they have trained staff, they have people who are there during recess and lunch. They have all the therapists are allowed to come into the school and do their therapy, which means, for the first time, I can actually start looking at doing something for myself because I don't have to get into all those therapy things; the therapists can come to him in the school.

Peter (16:30):

So it's a one-stop-shop for want of a better term?

Luana (16:33):

Yeah, but trained people who understand autism. Like I said, mental health trumps everything. I want him to be happy. I want to do everything I can to prevent... In his teenage years there's such high statistics of suicide, of depression. And I want to do everything I can. And if it means I have to move from everything I know here to move to another state, I'm willing to do that for him.

Peter (17:00):

How are you going to afford to do that?

Luana (17:02):

I can't. To be honest, the only way it can happen is if affordable accommodation comes up and-

Peter (17:12):

Close to that school.

Luana (17:13):

Close to that school. So I've been in contact with a couple of agencies over there that help people to find affordable accommodation. Unfortunately, I can't get on the housing commission list there because I don't live there. Yeah, I can't actually get there unless affordable accommodation comes up somehow. So it's kind of like the catalyst of me being able to get there is dependent on affordable accommodation. And I've been looking at accommodation over there. And currently I'm on Job Seeker. So at the moment there is nothing that would be affordable yet, but I'm been in contact with some agencies over there that may be able to help. There's a philanthropist. Is that the word?

Peter (17:58):

An individual who likes donating to worthy causes?

Luana (18:02):

Yes. And a politician that are looking to help the homelessness crisis down in the peninsula. And they're looking at putting tiny houses on the back of people's properties. So I am just waiting with baited breath that maybe I could even be the first person that they do this for because it's just something in the pipeline. But-

Peter (18:24):

Would Ollie be the first child from interstate to come to this school?

Luana (18:29):

I don't believe so. I think there's a lot of families who are in our position who realise that we need to move to get the right support for our children, which is sad. But yeah.

Peter (18:40):

Is it a model that could be... Is there enough call for it, say in Tasmania, that you wouldn't have to move?

Luana (18:48):

Definitely, in my opinion. Definitely. Yeah. But there isn't. There is special needs school here down in the south. And there is Giant Steps up in Launceston. But yeah.

Peter (19:02):

Nothing purely aimed at autistic children?

Luana (19:05):

There may be?

Peter (19:06):

Yeah.

Luana (19:07):

Please let me know. But not that I'm aware of.

Peter (19:12):

And the model that you see at this school is going to suit Ollie?

Luana (19:16):

I hope so. I hope so. Look, it's a big thing, as any parent would know, moving a child. But I think it's worth doing that step. It's worth doing that to see my son have friendships. Friendships that are nurtured and helped and staff that really understand. So yeah.

Peter (19:47):

Some people might say that he's mixing with other children that have autism. And then not; children that don't and don't understand. And so perhaps when he gets out into the wide, angry world, he might again hit the barriers that he's experienced in other schools.

Luana (20:07):

Look, my son is pretty awesome, and I think he would do pretty well. He's very, very, very social. If you were to meet him, he'd be talking to you. I don't think he'd have a problem. What I do need to do though is nurture him through the tough school years. I think beyond that, he's going to find his people. My son's extremely gifted in technology. When I say technology, it's not about games; it's about him setting things up. I've got a friend whose mother picks him up and takes her to his house, and he fixes all her tech things. Gets her yoga streaming onto the television. And he's just got this mind that can work these things out. And it's quite exceptional really.

(20:57):

So I really feel very confident that if I can get him through these schooling years and with his mental health intact, because he has anxiety, and that came from starting school and just that pressure of wanting to connect and things not going right all the time. If he can get through school system, he's going to find his people, and he's going to thrive. But I just need to get him through this bit.

Peter (21:28):

And if that road is now being navigated by him with help and assistance, you then can achieve what you want. I think-

Luana (21:40):

Absolutely. Yeah.

Peter (21:41):

In the advertisements that I've seen, in which you've been used, I think your quote was, "I adore being a carer, but it can come at a cost to me."

Luana (21:51):

That is so true. Yeah. It does. It does come at a cost to you. And that's the person I am too in that I would do anything I could to help him thrive. And yeah, I do do that at the cost of myself because he is my priority. I think this year I've had a little bit of a, I guess, revelation in that I felt like I have to be able to provide a home, I have to be able to provide everything, everything's on me. And I think it just put so much pressure on myself that I couldn't function.

(22:28):

And so I've had a big re-evaluation. And in just the last month or so I've realised, do you know what? Ollie needs me now. And so do you know what? I want to do teacher's assistant now. Yes, it's not going to pay much. We won't be any really better off than what we are now. But I will be able to help other children who are on that journey. And I'll also have the holidays free for my son. I'll have it that he doesn't have to go to afterschool care. And so it's just been this big re-evaluation of, I can't do everything, and it's too much to put everything on my shoulders. It's just me, and I can only give what I can give. And yeah, I am on empty a lot because I try and give out, and I try and do everything I can for him. But yeah, just taking the pressure off myself a bit. And I think if Ollie's happy in school, that is my biggest catalyst for me being able to focus on me.

Peter (23:27):

But you're an advocate for people in your position, and you run events?

Luana (23:33):

Yes, I do.

Peter (23:34):

What sort of events do you put your energies into?

Luana (23:39):

Yeah, sure. David, he's the CEO of Carers Tas, so hopefully all of him. He's brilliant. And when I started being an advocate for Carers Tas, I met with him, and I said, "Look, David," I said, "there's all these courses, all these things online, all these things where you get an invitation to do this. And I said, "We as carers, we're on empty." I said, "If we get an hour to ourselves, we probably just want to go and have a cup of tea or a cup of coffee. I've got nothing left to sit down and do a two-hour online Zoom at the end of the day. I don't want to do that." And it's not just me. I've got a lot of friends who are carers, of course; we connect. And I just said to David, I said, "What we really want is something that's going to nurture us, that we come away feeling better, we come away feeling connected."

(24:30):

So David was so on board to help me look into that. So I run the Better Start workshops, but our workshops are primarily focused on, it's called Breathe, Nurture, Refresh. And we do things like pottery, we do painting, we get together for lunches. It's something where it's about you coming away feeling better than when you came.

(24:54):

And of course, at those events, people can ask questions if they want to know about carer impact statements. If they're just starting their journey, it's great to be able to connect. And I just think it's a wonderful opportunity that us as carers can connect, but also come around people who are new on that journey and support them. Because in the NDIS world, there's no written manual that you know what to do.

(25:19):

When you get a diagnosis for your child, it's almost like you have to navigate it yourself. There are things out there, but we want to come around those people and share what we've been through and what's worked for us and give those recommendations. So Breathe, Nurture, Refresh has been really wonderful for a lot of carers, and they've just been so happy to come along and really thankful for it.

Peter (25:41):

Have you formulated the curriculum, for want of a better word, for that program all on your own?

Luana (25:48):

I came up with Breathe, Nurture, Refresh, because they're the things that, as a carer, we're just craving; someone to see us, someone to nurture us, that connection and what we need. But it is under the Care2Serve runs Better Start, so the funding comes from Better Start. So we also have a focus on helping provide that information and connecting people to what's out there. But yeah, David was so gracious to let us be really flexible within that program to really provide something that a lot of carers are really thankful for.

Peter (26:33):

You identify as indigenous Tasmanian?

Luana (26:34):

I do. Not Tasmanian, actually. Yep.

Peter (26:39):

Yeah, well, explain that to us.

Luana (26:40):

I'm from the Dharug tribe, so in Sydney. But I am a part of the indigenous group SETAC here, down in Kingston and Cygnet. So yeah, I love being involved with them and being able to bring Ollie up in that culture and understanding. And there's lots of events that they hold. And yeah, we really love being a part of that.

Peter (27:01):

Overall, would you say you're optimistic for Ollie's future and your own?

Luana (27:07):

I'm definitely optimistic about life. I love life. I'm on a journey. And I think as special needs parents, the journey never ends because you lose your learning support coordinator, or there's a new person in the class that your child...

Peter (27:23):

And you're back to square one.

Luana (27:24):

You're back to square one. And I think having a bit of grace with myself that, "Hey, it's okay." I think a lot of us are in that position where we do need to change schools to find the right fit for our children. That also affects us as parents. It would be nice to have that great school community. And some people I know are very blessed to have that.

Peter (27:47):

But don't be hesitant if you think this is not right for my child?

Luana (27:53):

Absolutely. And we have brilliant teachers for Ollie this year, and they care for him. Every child is different. And I think as a parent, you know what works for your child and what doesn't. And I think also, it's not just about your child; it's also about you as well and how you feel supported and connected as a parent as well.

(28:26):

Like I said before about the Carer Gateway and Care2Serve, it's been so wonderful as a parent to have that resource for me and to know that there's people who do care. There's resources out there, there's counseling, there's help doing job skills and things like that. There's online yoga. I've never done it, but hey, there's things out there.

(28:51):

I think one of the greatest things that has happened for me through Care2Serve has been their retreats. I went on a retreat with other parents of carers. And also, the particular retreat that I went on had carers. So there were some that were caring for sisters, some caring for parents, and a couple of us who were caring for children. And to have that common bond and to realise how exhausting and how all-intensifying, how... I don't know if that's the word.

Peter (29:23):

All-encompassing.

Luana (29:23):

All-encompassing, yeah. How that is, and to realise that you're not alone. But also, honestly, I cannot rave enough about how much of a blessing that was for me. And it was just the most amazing timing, the retreat that I had earlier this year. And they have listened so much to the advice of us of what do we need on a retreat? Do we just want to be doing work, work, work? No. This retreat was just the perfect balance of a beautiful location, rest, nurture. We did art. It was this perfect balance. There was a lady Heather. And having someone who was there the whole time, who also had experienced being a carer in her life and could connect, it was such a healing, healing thing.

(30:12):

And it was three nights away, not having to cook. I was lucky enough that my mum could look after my child. But honestly, it was three days this year which came at the best time for me.

Peter (30:26):

You were just at breaking point, were you?

Luana (30:28):

I was, actually. But it was exactly what I needed, and I just can't... Yeah, so thank you enough to Care2Serve and Carers Tasmania for that. They run retreats all throughout the year. They have mental health retreats as well. They have dementia retreats as well, and also parents with children. And the biggest blessing. But I just really love the way that Care2Serve is really listening to what carers need. And it is so open to hear that. And I think if you're not connected with Care2Serve or the Carer Gateway, ring them up, connect with them, because there's a lot of things out there, and they're really making a difference.

Peter (31:09):

Luana, thank you very much for telling yours and Ollie's story.

Luana (31:12):

Thank you.

Peter (31:13):

If we have any technical issues, we might get him back in to help us fix them.

Luana (31:18):

Ah, look he'll have it sorted in no time, I tell ya. He might be here for a few more hours though. Thanks for having me. It was a real pleasure to be here.

Peter (31:26):

That was Luana from Southern Tasmania. Thanks for telling us your story.

(31:37):

If you care for a family member or friend, Carer Gateway can help. Carer Gateway can support you to navigate the maze of supports, connect with other carers, talk to someone confidentially, get help with your caring role, support with your goals and residential or emergency respite, all for free. Call 1-800-422-737 and press one. Or go to carergateway.gov.au. Carer Gateway is open Monday to Friday, 8:00 AM to 5:00 PM. If you've enjoyed this podcast, share it on your social media channels or tell a friend who could benefit from it and enjoy listening to it. I'm Peter Gee. Thanks for listening.