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Peter ([00:30](#)):

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. 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.

Sean ([01:20](#)):

Hi, I'm Sean. I'm 52 years old and I live on the beautiful northwest coast of Tasmania. I live with my husband and I care for my brother who is 47 years old.

Peter ([01:32](#)):

Sean, thanks for inviting us into your realm. You can describe it for us, but Audrey Hepburn's over there in the corner, we've got a leather man looking down upon us. Rodin's thinker over there. This is an amazing place. Set the scene for our listeners.

Sean ([01:49](#)):

So I have a lot of items belonging to my family. So we have lots of 1960s and '70s pictures, ornaments, china that we use. Everything from the Wizard of Oz, as you said, Audrey Hepburn, Spanish ladies. So it's all here except the kitchen sink.

Peter ([02:07](#)):

Oh, that's in another room.

Sean ([02:08](#)):

That's in the next room.

Peter ([02:09](#)):

Yeah. Look, we won't go on a tour of the house, but who lives in this household with you?

Sean ([02:14](#)):

So I live here with my husband Ryan and my brother Tim.

Peter ([02:19](#)):

So the three of you?

Sean ([02:21](#)):

That's it. Just the three of us.

Peter (02:22):

And you care for Tim?

Sean (02:23):

For Tim, yes. So I've been caring for him since he was basically born, which is 1975 and I was six.

Peter (02:33):

That's a bit of a responsibility for a six year old. What are Tim's issues that he needs caring?

Sean (02:39):

So he's been diagnosed as a low IQ, so about the 67% IQ mark. And even though not officially diagnosed autistic, he exhibits a lot of characteristics of autism.

Peter (02:58):

And from the age of six, your parents said that you've got to look after your brother.

Sean (03:07):

Basically my mother was always ill and in hospital and my stepfather was always at his mother's house. So I was left alone a lot of the time to care for my brother or both my brothers, because I do have another brother.

Peter (03:24):

I find that hard to comprehend that a six year old would have the skills to be able to handle that.

Sean (03:31):

I think you learn very quickly because you're just thrown into the deep end. So my mother, when she found out was beside herself.

Peter (03:40):

What? That your brother was disabled in this way?

Sean (03:43):

No, that I was left alone to look after.

Peter (03:44):

Oh, because she's in hospital.

Sean (03:45):

Yeah.

Peter (03:46):

Who did she think was looking after you?

Sean ([03:49](#)):

Well, she thought my stepfather was.

Peter ([03:56](#)):

You're cooking for yourself, you-

Sean ([03:58](#)):

No. So he did come home for that kind of stuff. But basically I would sit there and look after my brother, change his nappy, that kind of thing. And also keep an eye on my other brother who was running amuck somewhere in the house.

Peter ([04:12](#)):

You were going to school?

Sean ([04:14](#)):

Yes. So I'd come home and he would disappear, my stepfather and I'd be left at home.

Peter ([04:20](#)):

Okay. So after hours you were a carer when you were a primary school student?

Sean ([04:26](#)):

Yes, yes, when I was in grade one.

Peter ([04:31](#)):

But everyone survived to this point.

Sean ([04:33](#)):

Obviously we're still here.

Peter ([04:36](#)):

And you've got health issues yourself.

Sean ([04:38](#)):

Yes. Several health issues over the years ranging from heart problems, which is congenital through to dodgy hips, back, whatever, a lot of stress related illnesses. But being very lucky that depression isn't one of them. I've been so fortunate with that.

Peter ([04:59](#)):

You do seem to have a cheery disposition the few minutes that I've been in your company. That's just natural?

Sean ([05:07](#)):

I think so. You need to be positive. Well, I think you do. And whenever there is a negative, try and find something positive about it. That's been my philosophy my entire life.

Peter ([05:16](#)):

Because you've been hit with negatives, right?

Sean ([05:18](#)):

I think so, yeah. But also I think it's just a personality disposition as well. I've been raised around positive women and strong women and obviously that's rubbed off or it's genetic or nature nurture. I'm not sure.

Peter ([05:36](#)):

Tell us a bit about your heritage. You are a wonderful mixture. I think there's-

Sean ([05:42](#)):

Mongrels I think I'm called.

Peter ([05:44](#)):

German Jewish. Scottish and indigenous Tasmania.

Sean ([05:49](#)):

Exactly. So on my grandmother's side it is Scottish and English royal family. With my grandfather, his ancestor was Dolly Dalrymple.

Peter ([06:03](#)):

The aboriginal matriarch.

Sean ([06:06](#)):

Exactly.

Peter ([06:06](#)):

The first half of the 1800s.

Sean ([06:08](#)):

Yes. I can remember my great-grandmother who died when I think I was 10. She would actually take me around to different places and talk about Dolly and it was her great-grandmother, I think from memory and show me places of interest to do with the aboriginal culture.

Peter ([06:30](#)):

Dolly Dalrymple I think had 13 children.

Sean ([06:35](#)):

She had a few.

Peter ([06:35](#)):

So this part of the world is populated probably by quite a number of people that can trace themselves back to her.

Sean ([06:44](#)):

I do believe that there is a few of us.

Peter ([06:57](#)):

I would expect that Ryan's got to be a pretty understanding man to actually accept that his partner is full-time caring for the younger brother.

Sean ([07:08](#)):

Exactly. It's actually quite difficult I think no matter what your orientation is and what kind of relationships you are in that if you go into a relationship with someone and they have children or care for someone, it's going to put a whole different range of problems within that relationship. And really you need someone who's gentle, understanding, who knows when to step back and leave you alone. And also when you need someone to be there. And I'm really lucky that Ryan is exactly that.

Peter ([07:40](#)):

So he's married to you, but Tim is there all the time that you're a trio virtually.

Sean ([07:45](#)):

That's exactly right. There's never a Ryan and Sean. It's always a Ryan, Sean and Tim.

Peter ([07:53](#)):

And did you have to introduce Ryan to Tim and get permission from Tim to have this new man?

Sean ([08:00](#)):

No, I just told him. I'm really fortunate that Tim doesn't kick up a lot of fuss when it comes to things like that. So I just said I've met someone. We dated for a short time, went away together and got married.

Peter ([08:17](#)):

And he's going to be living in the house with us.

Sean ([08:19](#)):

And that's the way it is and yep, that's fine.

Peter ([08:22](#)):

How would you describe your relationship with your brother, Tim? You've been looking after him for so long now. I would think it gets strained from time to time.

Sean ([08:31](#)):

It does. The biggest issue is that I'm his brother and of course brothers do not listen to each other or siblings in general. So don't you tell me what to do. You are only my brother is what I'll get from him sometimes when in reality I'm his mum and his dad. And so that can be a challenge in itself.

Peter ([08:53](#)):

Tim is not here today for example so you do have a bit of respite in that regard.

Sean ([09:01](#)):

I'm really fortunate that Tim is actually high functioning and holds down a job and has had that same job for nearly 30 years. So we have very strong work ethics in our family and Tim has actually inherited that and so he went off to work early and has had the same job ever since. So I get respite during the day. It's just the before and after that's pretty full on. When it comes to his work, he's always anxious, high strung and that's because there's a lot of responsibility with his job.

Peter ([09:34](#)):

What does he do?

Sean ([09:35](#)):

So he is a garbologist or someone who collects garbage and he's always been on the bottom rung at work. But recently he's been given lots of responsibility and I think that is because of maturity and also he's in the routine all the time. So that's been a big positive for him.

Peter ([09:54](#)):

How old's Tim now?

Sean ([09:56](#)):

Tim is 47.

Peter ([09:58](#)):

And his skills have been recognised at work.

Sean ([10:02](#)):

Finally.

Peter ([10:03](#)):

Really? Yeah.

Sean ([10:03](#)):

Yes. We have pushed for many years for him to be pushed outside the comfort zone. I believe that nearly everyone should be pushed outside their comfort zone. When you have an autistic person in the house, it's routine, routine and more routine. So if I came into the kitchen too early of a morning, he would lose it. So he'd have a mini meltdown, you are not supposed to be in here, you need to be back in your bedroom. So that kind of thing. So when it's my time to be able to walk into the kitchen and he's in the middle of breakfast, I can actually do what I need to do. And that's just to supervise him. As he's high functioning, he can be fairly self-sufficient, his memory is shot, so he can actually not remember how to wipe a bench down or how to put the stove on.

Peter ([10:52](#)):

Or he's too lazy to do it.

Sean ([10:54](#)):

That has been an issue in the past. But generally he does forget after a certain amount of time. So he could be doing something for up to a year and next thing, no idea, hasn't got an idea what he's doing. So you have to retrain him. So that's a constant thing. And then he needs shaving, need to make sure that-

Peter ([11:14](#)):

So his personal grooming is something that you do.

Sean ([11:16](#)):

He would cut his face to pieces, even with an electric razor, he has known to gouge out pieces of flesh. So that's interesting.

Peter ([11:26](#)):

Not a good look to front up at work.

Sean ([11:28](#)):

Probably not. He'd be like Norman Gunston with bits of toilet paper all over his face.

Peter ([11:33](#)):

Well actually Bernie reminds me a bit of Wollongong and vice versa

Sean ([11:37](#)):

So yeah, things like personal grooming. So shaving for him, thank goodness he's nearly bald, so I don't need to worry about his hair, make sure he's toileted properly. He's generally pretty good with that. But you've got to remind him of certain things that he's got clean clothes, that his clothes are ironed, he's presentable, and then I have to take him to work.

Peter ([11:59](#)):

So the routine is the same day in, day out.

Sean ([12:02](#)):

Day in, day out.

Peter ([12:03](#)):

And that makes it easier for him and easier for you I suppose.

Sean ([12:06](#)):

So for me, I could probably do it blindfolded and asleep because it's something that we do all the time. When it's his day off, he actually sleeps in for an hour and a half to two hours, which gives me a bit of time to do what I need to do. My biggest issues are weekends where I'm exhausted by Monday. So Monday is my sleep as much as-

Peter ([12:30](#)):

Because you have him all day every-

Sean ([12:30](#)):

All day.

Peter ([12:32](#)):

Of those two days at the end of the week.

Sean ([12:34](#)):

We do get support now through the NDIS, but it still is a pretty full on weekend. And Tim is one of these people that can't leave you alone. So he will sit opposite me and go, what do you want me to do? What do you want me to do? What do you want me to do?

Peter ([12:50](#)):

Away from work, he wants direction.

Sean ([12:52](#)):

He needs direction and he can't sit down and do nothing unless I'm in the same room with him. So he'll only watch television if I'm in the room with him, which is fine because he tends to break everything electrical. So he's not allowed to touch the television, so I don't get any me time. Whereas my husband, Ryan will spend a lot of his time in his own. He's got his own little room, so we just leave him up there.

Peter ([13:20](#)):

Do you find your own personality as being smothered by your brother's or do you lose your individuality to some degree?

Sean ([13:29](#)):

That's an interesting point. I put my brother into care for a year and I didn't know who I was. So it's like, who's Sean? I don't have to get up in the morning and do this and make sure that Tim is okay and that he's not setting fire to my house and you don't know who you are. And also being a child carer because I also cared for my mother for the majority of her life because she was sick off and on. And then my grandmother and they're all gone now. It's like, yeah. So who is Sean?

Peter ([14:06](#)):

What's my purpose? But you've had responsible jobs as well.

Sean ([14:12](#)):

Yes.

Peter ([14:13](#)):

Why did they not last? You've worked hospitality. An antique dealer. Why aren't you still doing those things?

Sean ([14:21](#)):

Because I got too sick. And that's obviously from stress or genetic factors or whatever. And if you are working, you are always wondering now what the heck is he doing at home? Or you take him to work with you, which I have done. When I was in hospitality, I was actually very fortunate that they employed him as well. And I wasn't married at the time, so it was just Tim and I and we'd both go to work. Unfortunately, in some cases it is a package deal and in other cases it can be quite fun. As he's got older and since he's come home from being in residential care, he's changed so he's more independent, he's more funny. He's not so grumpy with me all the time. So it's been a nice past year since he's come home. It's a natural thing to feel resentment when your life has been turned upside down, whether you can't go out, whether you can't have anyone around you. So of course resentment is going to creep in.

([15:34](#)):

So when you're a carer, and I tell this to so many carers, don't feel sorry that you feel like that because it's a natural thing. Obviously don't do anything to make sure it happens, but don't feel guilty because it's part of the stress release of being a carer. So I have a debriefing with him every day. So actually I'll have two. One in the morning when I'm driving him to work, we discuss about what may or may not happen during the day, especially with the public and the tactics he can use to cope with that. And then when he comes home, we usually sit down for half an hour and he talks about what he's done, who he's met, who's annoyed him, what they've said. And generally it's putting things into context that he can understand. So he's not worried about stuff he doesn't need to worry about.

Peter ([16:37](#)):

You touched on his physical ailments. That work's taken a toll on him. What about yourself? You've had childhood heart condition and you've been limping around a little bit here I've noticed.

Sean ([16:54](#)):

Yes. I'm due for a double hip replacement with the first one being done next week.

Peter ([17:00](#)):

Has it got to a stage where it had to get done?

Sean ([17:04](#)):

Yes. So I was born with deformed hips and since the age of 12 I've been in constant pain and because I'm allergic to painkillers, that hasn't been an option in most cases. And now at 52 it's like, yeah, they don't work and the pain's pretty incredible.

Peter ([17:21](#)):

Should have you done something before this? Before it got to the-

Sean ([17:23](#)):

They kept saying no, I couldn't because I was too young.

Peter ([17:27](#)):

Okay, so you're going to have a double hip replacement.

Sean ([17:30](#)):

Eventually. Yes. So the first one is next week.

Peter ([17:32](#)):

And how long will you be in hospital?

Sean ([17:35](#)):

Four days.

Peter ([17:36](#)):

So what's Tim doing in that period?

Sean ([17:38](#)):

So we're actually really lucky. So in the last two years we've got the NDIS. So we've actually got help, which we've never had before. We've always done everything ourselves.

Peter ([17:50](#)):

Was that a decision or you didn't know that what was available to you?

Sean ([17:53](#)):

No, actually it's because he was so high functioning that no one will actually recognise there was something different about him or he had issues with processing information. I don't like using that there's something wrong with him because there isn't anything wrong with him. He just processes stuff different to the rest of us.

Peter ([18:12](#)):

That doesn't fit into any neat little boxes that our services recognise. Right, okay, we can deploy resources to help this family.

Sean ([18:25](#)):

This is exactly right. With say with Centrelink. Now Tim used to get Centrelink when he first came out of school, which was a special ed school. And until he got a job, obviously he was on the disability support pension. And now I've tried to get carer's assistance through Centrelink and I've applied six times and been told each time because he works, he's not disabled and he doesn't need caring for and apparently making sure his butt's clean or giving him a shave is not caring for somebody.

Peter ([19:04](#)):

How would you advise people listening that find themselves in that situation? How can they navigate it best and get the outcome that they require?

Sean ([19:15](#)):

They really need to keep pushing. For me, I just gave up after six goes and financially we're all right, so we are really lucky. But if other carers are having issues, they need to find an organisation that could do advocacy for them or have someone with them to go in and talk to Centrelink. And of course you need

lots of medical evidence, so you need to know how to navigate the medical profession and that can be very interesting, especially if you get a doctor who doesn't understand.

Peter ([19:55](#)):

Have you sought assistance from the field such as Care2Serve, to try and do these things to make it easier on you?

Sean ([20:06](#)):

When it came to Centrelink, no, I pretty much did that all of myself. I have used a couple of organisations in the past for different things, but not to do with Centrelink.

Peter ([20:19](#)):

Even when you're at the end of your tether from time to time.

Sean ([20:23](#)):

Even when I was at-

Peter ([20:23](#)):

You still thought you could do it yourself.

Sean ([20:25](#)):

And I strongly suggest that no matter how smart you think you are or how laid back you are, get some help, just go and find the help and things like Carer Gateway will actually do that for you. They will interview you, talk to you on the phone, see what you need, and then they will put you in touch with whoever you need to talk to.

Peter ([20:50](#)):

And will they actually, while you are talking about the person you're caring for and what their needs are, be assessing you as to how they think you might be coping with this job?

Sean ([21:02](#)):

Yes. So I used to get help from Carers Australia, which is pretty much the same thing. And I actually did some courses on different things, which has helped me immensely. I have a teaching background for early childhood, so that helped me with Tim. But the courses I did was actually on dementia and self-care. The dementia course was brilliant and though it didn't apply to Tim as such, even though the doctors have said he may get early onset dementia, it helped me because some of the tactics that you use works very well with Tim for someone who is a dementia patient. Also, you learn a lot of stuff about yourself. How do you help yourself to help the person you're caring for? And this course was amazing.

Peter ([22:02](#)):

I would've thought it's imperative that you do have to look after number one from time to time if you are going to be able to properly look after number two.

Sean ([22:10](#)):

Definitely. So from experiences both bad and good, I have learned that mental health is really important. And as I've said before, I'm really lucky that I don't have, I'm not prone to depression or anything like that, but I know a lot of people under stress are. The other ways you need to care for yourself is don't beat yourself up and don't have expectations that are too high because you are doing the best you can. The other thing I found was that other people will judge you quite severely. So as a carer, you need to basically don't care about what other people think. You are doing the best that you can and there's no rule book and you just with help when you can get it, just do what you need to do.

Peter ([23:02](#)):

I've heard the term carer's dementia even, carer's fatigue. Have you ever been felt yourself getting near those?

Sean ([23:11](#)):

So the seminar that I did on dementia brought up a phenomenon called carer's dementia or caregiver's dementia. Whereas you're so stressed or under the pump or physically tired that you tend to have very similar symptoms to dementia. So forgetting, irritability, brain fog, which also makes you feel useless as a carer because you think, oh, there's something really wrong with me. And there's not. It's just the stress. Fortunately, it is one of the dementia things that can actually be reversed. So with proper self care, you can pull yourself out of that situation and feel reasonably normal to what you usually are.

Peter ([24:00](#)):

Do you think rest is the number one go-to if you think you're in that situation?

Sean ([24:06](#)):

Yes, I'll tell you a little story, Peter. When I was younger and caring for Tim, I would actually employ someone to come into our home for the weekend. As I said, I'm really lucky that he is self-sufficient. So they would just come in, make sure he is eating, clean, whatever. But I'd actually travel to Hobart, hire a hotel room for three days and sleep. So I needed that breakaway and it needed to be a long way away from where I live and I wouldn't have the phone on or anything, I would just sleep. For me that worked. Other people don't have that luxury. So you need to find something that is relevant to you or you enjoy doing and follow that.

Peter ([24:51](#)):

And don't feel guilty about it.

Sean ([24:53](#)):

Don't ever, ever feel guilty because you're doing your best.

Peter ([25:00](#)):

You're going to be a new man when you've got two new hips. But Tim is younger than you and he seems like he's as fit as a fiddle. Do you envisage a time when you are not going to be able to look after him and he's still high on healthy?

Sean ([25:19](#)):

Well, actually, the only thing I've ever thought about for many years is what do we do with Tim when I'm dead and a few years back when I was trying to navigate around the NDIS, I wasn't getting anywhere and I said, look, I just need some help. The longer I'm around, the better it is for the government or for Centrelink. I can still care for him, but I just need a little bit of help. And the response was, you're quite capable of looking after him, but don't worry when you are dead, he'll be cared for.

Peter ([25:54](#)):

That placated you I bet.

Sean ([25:56](#)):

That made me really happy. So actually I think that really annoyed me so much that it got me into gear to actually navigate the NDIS with a little bit of help. And that was from, again, Carers Australia, but I did most of it myself. And as I said, finally we got NDIS a couple of years ago.

Peter ([26:18](#)):

So you think things are in place for when you are no longer here?

Sean ([26:25](#)):

Because I'm having surgery on Tuesday, and even though the mortality rate isn't high, you have to be prepared. So my cremation is prepared where I'm being dumped when my ashes are prepared is being done. What will happen to Tim when I'm not here? So I actually have carers and support workers and other people that will actually come in and look after him.

Peter ([26:55](#)):

They might be dead by the time you die, though.

Sean ([26:57](#)):

Hopefully. I intend to be around for a very long time. But as morbid as it is, it's practical. And if you are the sole carer and because I don't expect my husband to be a carer to Tim because it's not his responsibility and he's a lot younger than I am, so he has a long life ahead of him. You need to make sure for your peace of mind that things are in place. And yes, a lot of people don't like to confront death or what may be after death for their loved ones, but once it's done, it's done. You can have peace of mind and go on with your life because that part, as horrible as it is, is fixed. And just revisit it every now and then to update things or to make sure that, because things obviously change in the caring field that they're going to be cared for. But it's easy if you know it's done.

Peter ([27:51](#)):

That gives you peace.

Sean ([27:52](#)):

Peace of mind. So when I go under the knife on Tuesday, I know everything is in order. Tim's being looked after, Ryan's being looked after, and I can wake up and come home and get back on with it.

Peter ([28:05](#)):

Sean, thank you very much for telling us your story today.

Sean ([28:08](#)):

Thank you.

Peter ([28:09](#)):

And yeah, have fun in the operating theater.

Sean ([28:12](#)):

I shall, I'll have a cutting good time.

Peter ([28:16](#)):

Thanks to Sean from Tassie's Northwest for telling us his story. And by the way, his hip surgery was a raging success. 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.