Isabella (<u>00:00</u>):

She was a bit ashamed of the situation. Where she felt like she wasn't being a good enough parent, and it took a while for her to be like, "Okay, I am sick. It's okay to accept help. I don't have to be mama bear all the time." And that was the biggest stage that we went through, which is her and all of us accepting this is what's happened. How do we help one another through this?

Peter (<u>00:33</u>):

Hello, I'm Peter Gee. Did you know that one in six Tasmanians are a carer? The 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 1 in 6 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.

Isabella (<u>01:22</u>):

Hello, my name's Isabella and I live in Tasmania on the northwest coast. I care for my little brother Samuel and my mum.

Peter (<u>01:29</u>):

Isabella, thanks for having a chat with us. In this series of podcasts, you probably have the honor of being the youngest carer that we've spoken to.

Isabella (<u>01:39</u>):

That's awesome.

Peter (<u>01:41</u>): How old are you?

Isabella (<u>01:42</u>): Me, I'm 16 years old. I just turned 16.

Peter (<u>01:46</u>): And how many of your 16 years have you been a carer for?

Isabella (<u>01:52</u>):

I'd say majority. So it started about eight years ago or a little bit more than that. So that's when mum had a first stroke. So my sister and I took up the role of caring for mum and my younger brother. So as soon as my sister graduated from college, she went interstate to study and then I became a little young carer on my own. So it's been interesting.

Peter (02:13):

That's a lot of responsibility. Did you think you were up to the task, or in fact, did you even consider yourself a carer?

Isabella (<u>02:20</u>):

Honestly, not really. If I had to do it again, I'd do it in a heartbeat. The way I looked at it was mum's raised us kids for the past however many years we've been here, and it was just kind of my turn to do what she's done for us. So I didn't see it as a job. I didn't see it as a caring role. I just saw it as love or just what I do normally. Until one day, I think it was at school, my GP, they asked me, "Did you know you fit into the caring role?" I was like, "No, I'm just a teenage girl. I'm just doing the bare minimum I can do." She's like, "No, no, no. You're doing more than the bare minimum. You're actually a carer." So from there I learnt all the new things and how I actually have support around me, which I struggled a fair bit, not knowing I had that.

Peter (<u>03:08</u>):

So initially you were just doing the caring instinctively. You knew what your mum wanted.

Isabella (<u>03:15</u>):

Definitely.

Peter (03:16):

Did you have know... how were you allowed after your mother's had a very serious medical episode to actually... Were you her sole carer initially?

Isabella (03:25):

So initially it was more my sister who did a lot of the raising, not raising, but caring for myself, my little brother. And I think I just followed into her footsteps of, "Okay, well she did this. I should be doing that too." Or even just trying to help around the house or give mum her medication. I just thought that was a normal thing to be doing, especially because I was very young when it first started. It was just kind of how we were as a family.

Peter (<u>03:54</u>):

But was there anyone else, like medical practitioners, coming in to oversee your mum's recovery?

Isabella (<u>04:02</u>):

For a while she did go to rehab to learn how to walk and talk again, and we would visit her in hospital, but we didn't actually have a respite team. We didn't have any of that, and we didn't really have people coming in to check in on us, especially mum's very stubborn in a way where she will walk and she will talk again. She very much is persistent to what she does. So I think...

Peter (<u>04:26</u>):

The family motto is, deal with it and move on.

Isabella (<u>04:30</u>):

Pretty much. There was a lot of, "Okay, well, she's walking, talking again." And she is very capable of doing everyday activities, but during that time we were doing the best we could in helping and we didn't have a whole heap of support until we found out about the carers network.

Peter (04:51):

We might talk about that a little bit later on, but initially you're trying to combine school work, I take it.

Isabella (<u>04:58</u>):

Definitely.

Peter (04:59):

Looking after mum, and we might get onto your brother. You mentioned caring for... His name's Samuel. What caring did he require?

Isabella (05:10):

So he was born three months premature, which meant that he would have some learning difficulties growing up. So he did get diagnosed with high functioning autism. So during his earlier years of growing up, I was his punching bag where he'd lash out to me if he had a bad day or because he didn't know how to socialise well and he didn't know how to express his feelings, he'd just come and hit me or he'd come and yell, things like that. Because I was the closest sibling to him and because I was always there for him, I think he took that as not a target, but I definitely was a punching bag.

Peter (<u>05:47</u>): For his frustration?

Isabella (<u>05:47</u>):

His frustration was let out on me, which...

Peter (05:53):

Did you accept that or did you punch back like most siblings would?

Isabella (<u>05:53</u>):

I definitely did punch back a fair bit, I will admit that. But I talked to, I think it was my GP again, and I said, "Look, I don't know how to deal with this." And she said, "Well, here are some strategies instead of getting angry at him, you could try seeing it from his perspective where he doesn't know and he doesn't understand what he's doing is wrong." So from there, I'd sit him down and I talk to him and try and find the root problem of why he's lashing out. So it could be...

Peter (<u>06:20</u>):

Was he able to actually verbalise to you what or why he was feeling that way?

Isabella (<u>06:27</u>):

Absolutely not. No. So not until maybe... He's 10 now, so it was only until he was about seven or eight, he could actually fully talk and express his feelings. Even then he was still a little bit of a pain in the butt, but it used to be as simple things as playing cards with him. I would do that instead of getting mad at him and he would be fine.

Peter (<u>06:49</u>):

You'd distract him almost.

Isabella (<u>06:49</u>):

Yeah. Or just kind of spending time with him, which I think he needed definitely that one-on-one attention rather having our attention on other priorities than him, I think was the big factor of it all.

Peter (<u>07:03</u>):

So at the same time, your mother is suffering the consequences of her strokes.

Isabella (07:18):

So everything happened pretty much at the same time. So Sam was born, we knew that he would have some issues growing up, and then mum unfortunately became unwell, so she even had things with the pregnancy that wasn't too great. Stitches broke, had to go back down, so I cleaned it up when it was infected, things like that.

Peter (07:39):

How is that to... Because that's an intimate thing to do for even a loved one. It's not something that you are expecting to have to do.

Isabella (<u>07:49</u>):

Honestly, it started off with my sister and I playing rock, paper, scissors and whoever lost had to do it. So unfortunately I was the sucker that lost. But no, it wasn't...

Peter (<u>07:59</u>):

How was it the first time?

Isabella (08:00):

The first time though, I thought... I was scared. I'm going to be honest. I was scared that I was either going to hurt mum or do it wrong because no one taught me how to sterilise an infected wound. I was maybe seven or eight years old. I was young, so nobody really taught me if the stitches break, you need to tell someone or if it becomes a weird smell, you need to definitely make sure you get someone to have a look at it. So I would just clean up the wound and put some cream on it and say, "There you go. It's all done."

Peter (<u>08:31</u>):

Well, after having done that, anything else is going to be a breeze, isn't it? It was sort of being thrown in the deep end.

Isabella (08:37):

Pretty much. It was just kind of the way we were as a family. I didn't look at it any differently. It was just you did what you had to do and you'd just move on from it.

Peter (<u>08:48</u>):

How was your mother at that stage when she knew she had a son who needed mothering? And she wasn't able to given her own health issues. How did she feel about handing on the motherly responsibilities almost to one of her daughters?

Isabella (09:06):

She was definitely very frustrated at herself, so she wasn't mad at anything, but she was mad at herself for not being able to help us kids. And she didn't accept that we were trying to help her. She thought it was pity because of, she's always always been mum. She never really had anyone to take care of her. So a lot of it was... I think she was a bit ashamed of the situation where she felt like she wasn't being a good enough parent, and it took a while for her to be like, "Okay, I am sick. It's okay to accept help. I don't have to be mama bear all the time." And that was the biggest stage that we went through, which is her and all of us accepting this is what's happened. How do we help one another through this?

Peter (<u>09:53</u>):

Tell us about your family situation. I think it would be fair to say it was a fractured sort of upbringing you had. Your parents separated and what progressed from there?

Isabella (<u>10:04</u>):

So growing up, mum was a single mother, so she raised us kids single-handedly. My father is obviously in the picture and every now and then would pop in. He was really good after mum's first stroke where he'd take us kids and try and help or even having mum at his house while she was recovering. So that was a really nice kind of family time, which we didn't have a whole heap of the time, but growing up we lived four hours away from dad. So every weekend we'd come up and see him and then we'd go back to where we lived. But it was just mainly my siblings, myself and mum. There wasn't really much to it.

Peter (<u>10:49</u>):

There was a time though, wasn't there, where you didn't have somewhere to live.

Isabella (<u>10:53</u>):

So unfortunately that was around the time Samuel was born. So having a newborn baby who's premature and single mum not really having anywhere to live. We had my German shepherd and birds as well. It was a bit of a fun time. We slept in our car for a while and went on to housing and different things in between then. We had to live at pubs and different housing commissions before which we settled down and bought our own house. So during that whole process, it was all mum raising us kids and getting work and getting everything sorted together whilst having to look after a newborn baby and taking us to school. And even then it was just... I was really young, I didn't see it. I saw it as an adventure kind of thing. I was like, "Oh yeah, this is fun. A new place each week."

Peter (<u>11:51</u>):

Do you think that might have had something to do with bringing on your mother's strokes or?

Isabella (<u>11:56</u>):

I definitely think stress was a factor. After her stroke, we were fortunate enough to find that she does have two rare neurological disorders, so they were the factors of the stroke. So she has a brain infection, and what happened was it grew bigger and started pressing down. So that led to...

Peter (<u>12:15</u>):

This is an abscess almost in the brain.

Isabella (<u>12:16</u>):

An abcess in her brain. And she also has an autoimmune, so she's got a fair bit going on. And it wasn't until her second stroke that we actually found out all of this. She'd go for testing after testing, trying to find the root cause of what's happening, but it took at least eight years before we knew what's going on and how to treat it. And still till today, she's just got so much going on that new things are popping up and we're trying to figure out what's what actually is happening. But she's a stubborn one.

Peter (<u>12:52</u>):

She describes you as resilient and compassionate. You've not heard her say that out loud?

Isabella (<u>13:00</u>):

We have a very interesting relationship. No, we love each other dearly, but I don't think we actually have enough time to spend with each other and actually be like, "Hey, you're doing a good job."

Peter (<u>13:13</u>):

Well, here's an opportunity for you to describe her. She's a force of nature. I've spoken to her on the phone and that's how I... She's like a whirlwind and she's a really good talker. How do you describe your mother? She's had a colorful life, I think we could say.

Isabella (<u>13:32</u>):

She is just a stubborn old thing in my eyes, in the nicest way possible. I don't mean that, but no, she's like a mama bear when it comes to her children. She's fierce as anything and she always puts everything aside just for us kids. I remember once I was craving a coffee frappe from Maccas, so we went to the Burnie one, they were completely all out. She drove all the way to Launceston to get me a coffee frappe because I was craving it. She took an hour and a half to get me a \$5 drink and I was like, "Oh my God." I started crying and she's like, "This is what mums are for."

Peter (<u>14:17</u>):

Tell us about her background.

Isabella (<u>14:20</u>):

So mum is Indian, she's fourth generation Singaporean, so she grew up in Singapore and came out here on a scholarship. And my dad is Australian.

Peter (<u>14:32</u>):

You moved to the northwest coast where you are now in Tasmania and found quite a welcoming community, I believe.

Isabella (<u>14:39</u>):

Everyone was actually really supportive and I didn't... Growing up because we used to live down Southway. I was really, really young when we moved up here, so I was maybe about six years old. But being here, we had so much more support than what we knew we had in a way that friends and what we call as family. They would just come and they'd bring us food and they'd cook whilst mum couldn't cook, or during her recovery, they'd take us kids out. My auntie once took me out to Launceston for the day to go watch movies or someone would always just be there for us kids so we wouldn't have to be the adult in that situation.

Peter (<u>15:18</u>):

Was that the cultural sort of identification that you have that helped you in that regard? Was it having Indian background?

Isabella (15:28):

There's a beautiful Indian community up here, so I've got quite a few aunties and uncles is what we call them. Even the white Australians here, they were really, really supportive of us and we made quite a few meaningful connections, which we still have till today. So just even at the hospital when Sam was born, there was a tea lady, she unfortunately has passed away now. But Auntie Robin and she took us in when we didn't really have anywhere to stay and she helped support us throughout this whole entire journey that we've been through. And she herself had some very severe health issues and unfortunately now she passed away I think last year. But up until then, she was making sure us kids were okay, mum was okay, and even my dog and birds, she took them in and looked after them as her own because we couldn't have them where we stayed.

Peter (<u>16:21</u>):

That must have been a bit of a surprise and a welcome surprise given that you were arriving in a new place, in a dire situation, really.

Isabella (<u>16:31</u>):

Definitely. She took us in as if we were family, which was just amazing to see how beautiful and sweet she was. And we met her family as well. So it was just having more family that we could have.

Peter (<u>16:46</u>):

Do you think that was down a little bit to your mother's personality, that she is so outgoing that she almost welcomed these or brought these people into your sphere?

Isabella (<u>16:49</u>):

Definitely. She definitely, all the connections I've made and everything that I've done till today, it's always been mum that helped me do it. School wise, she's always been there to push me at the best I've been. And even talking to people. She has that way where she can just communicate so great and she just brings out another side of people that nobody else has seen, and I think that's what's happened, which is amazing. She's an amazing person.

Peter (<u>17:25</u>):

How is her health now? Are you still caring for her day by day?

Isabella (<u>17:31</u>):

So now she does have a fiance who's stepped up a lot and helped, but that wasn't until about two years ago. And even then they're kind of on and off again. But her health has gotten significantly worse, unfortunately. When you look at her, you think she's just a bright young person who has the whole world to face. She has been through a lot and a lot of people don't see that other side that we see

where she's in bed and she's struggling or she's on opioids and sedatives because she has seizures at night and I'll be there looking after her.

Peter (<u>18:07</u>):

What's sort of an incident that might happen? How are you aware that she's in trouble?

Isabella (<u>18:11</u>):

Honest to God, as soon as it goes quiet, I'm not joking. As soon as it goes quiet and you can't hear us speaking, you know something's wrong. So a lot of the time it happens at night, unfortunately. And that's when I sleep next to her to make sure she's okay. And she does have seizures throughout the night, and that happened really recently. So my sister graduated from the northwest coast and moved interstate to do university. And unfortunately during that time, that's when all this new stuff was happening. So I myself, I don't know what I'm doing and I didn't know how to cope in the best way possible. I didn't think about my mental health or physical wellbeing, which I was mentally frustrated, not at the situation, but because I couldn't help mum. I couldn't help the condition that she's in and I couldn't fix the problem and I just had to watch her suffer in a way where she couldn't communicate while she was seizing. I couldn't stop it and I didn't know what to do.

Peter (<u>19:17</u>):

That must have been frightening.

Isabella (19:18):

It was definitely, unfortunately this year on her 50th birthday, I had to give her CPR because she stopped breathing. She had another stroke. And before, actually during all that, she had a huge seizure. I put her into the recovery position. My sister and I were on the phone with the ambulance crew. I was doing chest compressions. My sister was doing mouth-to-mouth. We did have a little debate of who's blowing in mum's mouth. I dibs not it.

Peter (<u>19:45</u>):

I looked after her stitches all those years ago. You can do that.

Isabella (<u>19:48</u>):

You can. It's your turn now. But even during that time, it was just like an adrenaline rush where you did what you had to do. And looking back at it was like that is a very significant part of my life that has happened, how to cope during that. And I didn't want to talk about it for ages. I didn't know how to talk about it. I didn't know how to go to mum, be like, "Hey, you died. Are you okay?" We just kind of moved on from the situation, didn't talk about it for a while.

Peter (20:22):

Have you got some more tools now to deal with that situation if it should arise again?

Isabella (20:28):

So fortunately I did a school first aid course and that's how I learned how to do CPR and learn how to actually look after mum in some aspects. But I did recently did another first aid course and I shared my

story and I learned new things about other people's journeys and how they cope. I also do see a psychologist just because it does... It gets very, very difficult caring and I learnt how...

Peter (<u>21:00</u>): Who pays for that?

Isabella (<u>21:01</u>):

I think it's definitely mum, but I think we organised it through a GP and stuff. So my doctor surgery is absolutely amazing and they've always been a huge support. So they basically did everything for us in learning that there's Carers Tasmania or Carer Gateway, I think it's called, and organising psychology.

Peter (<u>21:27</u>):

What help did they give you? Care2Serve.

Isabella (21:28):

So they have done a whole heap. So this recent first aid course I did was through Carers and I'm really fortunate enough to hand an application to become a cadet through St. John's. So that's a little goal that I have.

Peter (21:46):

Is that something that you'd thought about before you actually treated your mother almost instinctively?

Isabella (21:52):

Honestly, I never had that time to think about it. I've always wanted to go into medicine, so palliative care is what I want to specialise in and I think it definitely is caring for mum and having her almost not being here has been a very big impact in my life. And I've loved caring for her and I love helping her and just seeing her smile and bounce back up. That's what I want to see for everyone. So even if they can't, it would be nice to have, I think I see myself as a very nice, supportive, caring person and knowing that a goodhearted person is there to care for them during their last kind of years, that's important to me.

Peter (22:37):

What about caring for yourself through all this, your traumatic 16 years at various times? Has that been a priority or something that you've perhaps neglected?

Isabella (22:49):

That definitely was neglected until about last year or the year before. I had quite a few mental breakdowns and getting higher up in high school. There was caring for mum, there was high school kind of bullying, things like that, which I took to heart a fair bit. I didn't know how to cope. And by then my sister, she wasn't here, she was interstate. So I felt very alone and I felt very ashamed of myself in a way where...

Peter (<u>23:17</u>): What? For weakening in your mind? Isabella (<u>23:18</u>):

For not actually being able to stand up for myself, that's what I thought. And I learned that I shouldn't ever be ashamed of myself because it's nothing to be ashamed of. The young Carers Network have little meetings and I've been encouraged to go and just, I don't even have to say anything. I just sit on my laptop and hear other people's perspectives on their caring role, which I think is absolutely amazing. Unfortunately, those times run whenever I'm training.

Peter (<u>23:56</u>): Training for what?

Isabella (23:57):

So I do a lot of martial arts, so I specialise in karate. So I've got a black belt in karate and became the youngest karate instructor in my club, which was awesome. So I got my black belt at the age of 14 and became an instructor at 14. So I have a little class that I run every week.

Peter (24:16):

This started pretty early, didn't it? This karate career, if I can put it that way.

Isabella (24:22):

Absolutely, yes. So I started at the age of four and I always just... Mum got us into it, especially being young and female. We just started doing it and I saw it... I knew I was passionate about it, but I didn't think it would get this far. I really thought that I would just continue to train and that was about it. But I entered in competitions and made it to Nationals States World Cup. So I came in forth at the World Cup and just continued to progress up, which is awesome.

Peter (24:50): Did it become a bit of an obsession for you?

Isabella (24:52):

Definitely did. For a while, I stopped going to school to train instead, which is not healthy. Definitely go to school kids.

Peter (25:03): Did you think you could become professional perhaps?

Isabella (25:05):

I just thought that it mattered if I was training where I couldn't stop training, if that made sense.

Peter (25:12):

Well, you thought you were letting yourself down every time you went away and did something different, you could go backwards.

Isabella (25:18):

Definitely. And it was a lot of a mental struggle where I didn't see the perspective that everyone else saw it as if I was obsessively training. It took hold of me and it did definitely consume me, I was to the point where I had broken ribs and my black belt because of how hard I worked to accomplish that. But the tiniest hit my rib, it broke. So that was definitely both a mental and physical journey where I had to heal. So I wasn't allowed to train obviously for a couple of months. And during that time was my reflection period.

Peter (25:59):

And you thought this has become too all encompassing. I need to be...

Isabella (<u>25:59</u>): I saw how obsessively I was training, four hours every day was a lot. And I didn't...

Peter (<u>26:08</u>):

And then you'd get home and care for your...

Isabella (<u>26:09</u>):

And care for mum and brother and it was just like, "Oh yeah, it was another thing to do." But I neglected friendships during that. I didn't go out with friends. I didn't go to school because I was mentally and physically exhausted where I didn't get out of bed.

Peter (<u>26:28</u>): Did anyone else see this?

Isabella (26:30):

Mum and dad definitely saw it and tried to have an intervention with me. I did not listen and continued doing what I was doing anyway. Right before one of the biggest events of my life, I broke my arm two months before that.

Peter (<u>26:53</u>): What was the biggest event with your life?

Isabella (26:55):

So I made it onto the Olympic team and was meant to go of to Tokyo, but I did a stupid cartwheel with my sister to prove that I could do one again. Competition runs in the family and I went too far that it went snap and I couldn't go.

Peter (27:12): So an Olympic dream was snuffed out?

Isabella (<u>27:16</u>):

Honestly, I didn't see it going that far when I was little. And then as soon as I got that email and I went on to World Cups and I got all these certificates, it became an obsession where I just needed to continue doing it to keep achieving more and more. And I think that was the way that I validated myself a lot of the time. And that was my outlet of... It was like my mental outlet where I could just let my anger and frustration into a punching bag or I could have me time for a few hours just doing what I needed to do.

Peter (27:50):

So is that now something you've put behind you?

Isabella (27:54):

No. Well, the obsessively training, yes, but I'm still teaching and training, so now I don't train as much as I used to. So it's only an hour a day if anything, it took a while to compromise that. But it was definitely just... I took a while off to just focus on myself and heal myself.

Peter (28:21):

And representing your country might happen again, do you think?

Isabella (28:27):

So I actually got a little letter saying I could go into the trial team for Paris in two years. So that is the little goal that I will take a different pathway to and not do what I did before. So I'm looking at different healthy alternatives and training, eating definitely was a big part of it. And how to manage schoolwork and juggle caring and relying on people as well.

Peter (28:53):

And setting yourself up for a medical career, of focusing on palliative care. You've got absolutely nothing on your to-do list, have you?

Isabella (<u>29:03</u>):

Honestly, I have too much time on my hands.

Peter (29:04):

You've got a lot going on in your life, and I think anyone just hearing you talk would think there's a high achiever.

Isabella (29:12):

I try to be.

Peter (29:16):

So have you got anything you'd like to say to someone in your situation? A young person who has someone at home, a loved one, that they have been given the responsibility for caring for?

Isabella (<u>29:29</u>):

So even if it doesn't seem like it's a caring role to you, always try and reach out to support because there will be someone to help you.

Peter (29:38):

Accessing professional services, people who do this for all manner of carer. Would you recommend that? Getting onto the Carer Gateway and finding out here in Tassie, for example, what Care2Serve have got to offer you.

Isabella (29:53):

Definitely, no matter what age you are, whether you're a young carer or just a carer in general, it's definitely a great support crew that will help you in so many ways and they're just amazing sweet people.

Peter (<u>30:05</u>): Izzy, thank you very much for talking to us.

Isabella (<u>30:07</u>): Thank you for listening.

Peter (<u>30:07</u>):

I'm sure you've inspired a lot of people and I think, well, how can I ever keep up with that schedule that she's set herself. So thank you very much for telling us your story today.

Isabella (<u>30:18</u>):

No, thank you for having me, and thank you for listening,

Peter (<u>30:20</u>):

And we're looking forward to testing your mother's cooking skills. I think Pushba is going to look after us today.

Isabella (<u>30:27</u>): I hope so. I'm so hungry.

Peter (<u>30:33</u>):

If you care for a family member or a 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 1800 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.