

00:06 Douglas Connor: Hello and welcome to Choice and Control, a podcast celebrating the contribution people with disability make to our communities. In this series we are talking all things disability, social inclusion and the National Disability Insurance Scheme.

Throughout this series you will also be hearing some great practical advice for making the most of your NDIS Plan from local people accessing the Scheme. This podcast series is brought to you by the team at Carers Queensland, NDIS Local Area Coordination Partner in the Community. I'm your host, Douglas Connor, thank you for tuning in.

Today. We have a very special episode for you, we're lucky enough to be hearing from two incredible women who, with their families, have made Australia their home in recent years. Both women now reside on the Gold Coast and have family members with disability receiving supports through the National Disability Insurance Scheme. First we're hearing from Tsonkyni.

Tsonkyni came to Australia with her husband Trulku almost six years ago, after leaving her home country of Tibet to visit the Dalai Lama in India. The Dalai Lama is the spiritual leader of Tibetan Buddhism, and has been an exile in India since 1959 following a failed anti-Chinese uprising. Many Tibetans see the Dalai Lama as a living God and Tsonkyni and Trulku wished to visit him in India to pay their respects. Unfortunately, on their attempt to return to Tibet after their visit, they were not re-allowed entry. Tibet has been a place of political unrest for centuries, and in recent times Chinese authorities in Tibet have enforced penalties for those who choose to visit the Dalai Lama.

1:53 Tsonkyni Lhamo: My name is Tsonkyni Lhamo and I'm from Tibet. China, they control Tibet, so His Holiness the Dalai Lama lives in India. He can't go back to Tibet. We wanted to see him, that's why we went to India. The Dalai Lama is our God, so that's why we just

wanted to see him. So when I went to India, I met the Dalai Lama, and after that I tried to go back to Tibet but then China said 'No, you can't come.'

I went to Nepal and I tried to get a visa. I went to New Delhi and tried to get to China but no, you can't.

2:36 Douglas: For Tsonkyni's husband Trulku it was his second time visiting the Dalai Lama, with his first trip resulting in a year's jail time.

2:43 Tsonkyni: First, before we were married, he went to India, met the Dalai Lama, and then he came back to Tibet, no, he went to India and then China put him in jail for one year. After one year he was sent back home, but he said the Chinese police came every day and checked him. Then he come back again.

3:09 Douglas: Unable to return to Tibet, Tsonkyni and Trulku returned to India before eventually settling in Australia.

Tsonkyni and her family have now been in Australia for almost six years, and she says that being away from family is the hardest thing to adapt to. Unaware that their absence from Tibet would be a permanent one, the couple did not have a chance to say a proper goodbye to their loved ones.

Tsonkyni says that she regularly attempts to contact her family by phone, but worries about getting them in trouble with authorities.

3:35 Tsonkyni: We didn't understand [the permanence of] what we were doing. I didn't meet with all my family when I went to India because I was just thinking I'd go to India, meet the Dalai Lama, and come back home.

So I just went, I didn't meet with all my family, my sister and brothers. So it was very sad, and it's so difficult. I can't even talk with my family because China controls Tibet.

Last time my family bought a phone, and I spoke on it and I used the recharge, China came to my house in Tibet and they said 'You can't use recharge and you can't talk over the phone to people. You can't talk.'

They took my Mum's phone, and they took my Mum to China for one week. After that they sent Mum back, but they kept my Mum's phone. They said 'You can't talk anymore'.

Trulku's Mum is 85 years old. She's always asking 'when are you coming? When are you coming back?' When he talks to his Mum, she always says 'when are you coming back?'

4:41 Douglas: Tsonkyni's husband Trulku has a physical disability and receives support through the NDIS. Tsonkyni says that having access to NDIS support has made a huge difference to the life of the family.

4:52 Tsonkyni: They help with lots and lots of things. Not only Trulku, it helps the whole family. They take Trulku somewhere, and lots of things. It's better, the NDIS, they support us and I know some other people who get support with lots of things. Yeah.

5:15: Douglas Next up we'll be hearing from Fatima, an Australian-born woman of Turkish descent. Fatima is the mother of ten-year-old Mertcan. Fatima had been living in Turkey for close to 10 years when concerns over Mertcan's health and a changing political environment forced them to relocate back to Australia.

5:35 Fatima Firat: Mertcan is 10, 10 and a half I should say. He was born in Turkey. He was born healthy, just like a normal child, but when he was two and a half he was just so hyperactive. He would literally climb straight walls. His development skills were really good to his age, it was age appropriate. And then, he had an accident.

He took some aspirin. I was fortunate, there was an ambulance on site of our complex for another emergency, but they took him, and

he was in ICU for 72 hours. And then after he was discharged, about close to a week, I realised he was not able to use the words he was using, like two, three words that were age appropriate. He was using a lot of body language and making up little words of his own. And I knew there was something not normal there.

People wouldn't understand. They thought I was overreacting as a mother. I took my son to the docs and they also thought I was overreacting and everything. But when he was in hospital, the hospital doctor said there might be a bit of oxygen lacking at the time to the brain, but then they didn't take it on further, investigations weren't done.

And then when he was four - so what, what year and a half later? - I said I can see his development was really very behind. And that's when I decided to come back to Australia. Well, one of the reasons why I came back to Australia. Because I knew I would be able to find and get the support that he needed.

7:20 Douglas: Apart from ensuring that Mertcan received the best support available to him, the other factor in the family's return to Australia was the changing political situation in Turkey. Fatima says that Turkish society was seeing a shift back to outdated traditional values that her family didn't agree with.

7:35 Fatima: Also, another thing was the regime that's currently there. I wouldn't have been heard anyway, even if I had the money and everything, it's a very different outlook. It would have been very different, I wouldn't have got the support anyway.

It was a total opposite, like 360 degrees opposite to our values and ethics as a family. I'm Australian-born but descent Turkish, and obviously I have been brought up in a Turkish tradition and cultural families. My parents were educated. My father was very broadminded. Like, my father would help around in the house, you know, house duties, vacuum or wash or whatever. And his friend

would say, 'Oh, what are you doing? You know, that's a woman's work?'

He'd say 'Well, my wife's working too. So she's contributing to the house. I have to, you know, help her.'

So this is the way we have been brought up. So has my husband, his family.

8:43 Douglas: Fatima said that opposition to the ruling party's politics actually saw her husband lose his business.

8:49 Fatima: It's either his way, or you're in prison. My husband lost his business because he wasn't part of the regime. He went bankrupt. That's why I'm back here.

9:01 Douglas: Once back in Sydney Fatima began the search for a diagnosis and support for her son Mertcan.

9:07 Fatima: So I came out here and then my husband followed on afterwards, a year or so after. I found a really good neuropsychologist back in Sydney who did a cognitivity test and many other tests as well, and he was diagnosed with hypoxic brain injury. That's when I started to get some assistance, in Sydney.

When we moved up to the Gold Coast about four years ago and I took it on again, and then the school was very helpful. And then got onto the services with NDIS. He's receiving OT, psychology, speech, you know, occupational therapy, but it's basically on his cognitivity and so forth.

As a family, our goal is to actually get him able to be able to communicate, able to address his fears, also to be able to identify a few things like what's right and wrong, like bullying and rudeness and mannerism. We've come quite far, to the positives we have achieved. Now we're sort of trying to get onto the academic side now, to comprehend. And we're doing that at home as a family.

10:30 Douglas: Now living on the Gold Coast, Fatima says that Mertcan is thriving at his new school and working towards achieving his goals.

10:37 Fatima: He is at Broadbeach Public School. He loves it. And I love that school too, I think it's one of the best schools on the coast with its support networks and the facilities that they have. He's getting real good support there because of NDIS as well. They know about his situation, so he gets that extra support at school as well.

So he has speech and language therapy there. He has a psychologist there, a counsellor. He also has a one-on-one teacher for his English and maths to help him with the questions when he's not understanding. So he's there in class, but it's just focusing on Mertcan. It's done quite a lot.

11:22 Douglas: Fatima said that the support offered by the NDIS had far exceeded her expectations.

11: 30 Fatima: Absolutely fantastic. I have my own issues too, Douglas, so it becomes overwhelming. So when something is happening, I can easily get in touch with Mertcan's case workers and so forth and say 'look, I need some support and I can't do it because of my [challenges]', and they're straight away doing it for me, getting it done for me. That's why I'm very, very happy with the service. I think it's the best thing ever, they've acknowledged children with disabilities, that they need extra support. It's not that they're silly or whatever, they need a little extra support.

12:09 Douglas: Fatima also mentioned that she noticed quite a difference in the way that people with disabilities were perceived in Turkey and in Australia.

12:15 Fatima: I was actually teaching English at a private school in Turkey, and I had two students who were behind their own peers. But when I used to go to them and teach them and show them

things, one-on-one, that's it. They can do it. They just get that group thing. So I actually brought that up with the school counsellor at the time, over there. I said to him, 'We have these kinds of supports in Australia. I know that. Is there any support here in Turkey?' I mean, I wasn't educated in Turkey obviously, so I don't know the whole system.

And she just laughed at me. She said, 'This is Turkey. You remember that don't you Fatima?'

I said 'Yes, I do, but that doesn't mean that we're still living in 1960s or '50s.'

So they don't recognise it. And then when you start talking to the family, it's very hard for them to accept that there is something wrong because, it's what the community thinks, it's not what you think about your family. So it's very different

13:27 Douglas: Fatima says that now, after a couple of years, her son Mertcan and her husband are both starting to adapt well to Australian life.

13:32 Fatima: For Mertcan at first it was quite hard because, you know, he did miss his room, his belongings, he has an older brother back there. He does sort of vaguely remember him. But you know, as a child, four years old, quickly sort of overcame that.

But my husband, he still has difficulties. I mean, he was 60 when he came out to Australia. So it was very hard, but he's starting to understand and getting it, realising it.

14:07 Douglas: Fatima says that access to NDIS support made the transition to Australia a much smoother process for her family.

The family are now together, loving life on the Gold Coast. There are some differences however, with Fatima lamenting the lack of access to cheap European travel.

14:27 Fatima: Over a weekend, just a weekend getaway, I used to go to Greece. I used to go to neighboring countries and it was like, 40 Euros for a return ticket. 40 Euro! For 40 Euro I couldn't even get here to Coffs Harbour, forget about Sydney or Melbourne.

14:42 Douglas: That's all for today. A big thank you to Tsonkyni and Fatima for sharing their stories.

The National Disability Insurance Agency and Carers Queensland are committed to delivering the National Disability Insurance Scheme in a way that is sustainable, and responsive to the needs of our richly diverse and multicultural nation. Australia is a nation of peoples with many languages, ethnic backgrounds, traditions, and religions. More than a quarter of Australians were born overseas. More than 300 different languages are spoken, in addition to the hundreds of languages spoken by our Aboriginal and Torres Strait Islander peoples. Australians identify with around 300 different ancestries. I hope these stories provided some insight into some of the different ways that the NDIS is helping to support culturally and linguistically diverse people with disability in Australia.

Thank you once again for tuning into Choice and Control, a Carers Queensland podcast.

For more information about Carers Queensland, the National Disability Insurance Scheme or the Local Area Coordination program, please [connect with us online](#) or you can catch up with us on [Facebook](#).

We hope this podcast can become a place for people with disability to share their experiences and their stories. So, if you have a story you think we should know about, please contact us via the Carers Queensland Enquiries Line at 1300 999 636, or via email at cq.enquiries@ndis.gov.au

Until next time, thanks for listening.