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Diagnosed at 14 with Friedreich's ataxia (FA), a rare incurable genetic disorder, Tanesha Bolte-Hile was unsure what her future would hold.

The proud 23-year-old Biripi woman from Warners Bay said when she first heard her diagnosis she didn't understand what it was or what was going to happen.

'We were all in a room at the John Hunter Hospital. Dad and nan were bawling their eyes out, but I didn't shed a tear,' she said.

'Then I was told there was no cure. I still didn't understand, but now in 2023 I wouldn't wish it on my worst enemy. It's so cruel. It's taken the majority of my independence.'

Affecting her entire nervous system, Tanesha can't walk. She also has trouble concentrating, speaking and she fatigues easily.

The FA has affected her spinal cord tissue making it hard for her to control her arms and legs.

Living with her nan, Yvonne and Uncle Norm, the trio were grateful to learn the National Disability Insurance Scheme (NDIS) existed and it could help support them.

'The NDIS has done wonders. We can't thank them enough. They've given me a new way to see life around me for the best,' Tanesha said.

Living on Awabakal land, Tanesha has used her NDIS funding to engage a mix of services, including a few culturally appropriate Indigenous providers.

Through them Tanesha receives home, personal and community supports.

She attends the gym once a week and receives occupational and physio therapies.

She also has a range of assistive technologies to help keep her active.

'I've got a 360 Magic Mobility wheelchair. It's great. It goes anywhere,' she said.

'Nan and Uncle Norm bought me a blue Caddy car and my wheelchair fits in it perfectly.

'I love going shopping, so my support worker Edie and I use it to go to Charlestown shopping centre. I also like going to the beach, even if it's just to watch the waves.'

Tanesha said the support she receives has helped her feel much more positive about life.

'Darren, my Awabakal support coordinator has just been amazing. He goes above and beyond to make sure I have everything I need,' she said.

‘I’m also lucky to have Edie my support worker from Justiz. She’s just so lovely and we do so much together.’

A huge fan of the TV drama series Home and Away, Tanesha said she even got Edie to drive her 2 and a half hours to Palm Beach, the location where the show is filmed.

‘I wanted to see if I could meet Alf Stewart (Ray Meagher). He’s my favourite character and we did,’ she said.

‘We saw him sitting in a car reading a newspaper. I decided to go over and tap on his window. He was lovely. We had a chat. Now I’ve meet him I can rest peacefully.’

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