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Deanside mum of 3 Margie Mutambara can’t believe her daughter, Mia, is 12.

‘When Mia was born, and with the severity of her disabilities, doctors didn’t think she would make it to her first birthday,’ Margie said.

‘Since then every birthday has been so special. It’s been a remarkable journey – one I personally call my testimony, my miracle story!’ she added.

Mia was born with a rare disability called Lobar Holoprosencephaly due to a midline cleft lip and palate.

‘Usually when people have a cleft lip it just affects their lip, but when you have a ‘midline’ it’s neurological,’ Margie said.

‘Mia’s brain is mostly separated into 2 hemispheres but is incomplete and sealed together in places, so it has affects her ability to sit up unsupported, walk or speak.

Margie said from the time Mia was born there was talk of a ‘big dental surgery’ when she turned 12.

‘Specialists wanted to repair areas in her mouth and do a bone graph to add to her gum area so it would help her teeth growth in the cleft area but late last year a miraculous thing happened.

‘Two weeks before Mia’s hugely anticipated complex surgery, at her final appointment, x-rays showed teeth were growing in the gum scheduled for repair, so the surgery was cancelled!

‘Mia’s specialists said medically they couldn’t even say she ever had a cleft palate. They had never seen anything like it. It was a miracle!’ Margie said.

In spite of her other complex disabilities Mia, an NDIS participant, continues to defy odds and Margie says Mia continues to impress all who know her with what she’s capable of.

‘Mia loves going to school and enjoys regular occupational, physio and hydro therapies. They’re really helping her develop physically and mentally,’ Margie said.

‘She loves spending time with her family, being around people and she remembers faces!

‘We talk about how she might have the mind of a toddler, but I get wonderful feedback from her teachers, who say she continues to surprise them.

‘It’s incredible she understands what’s going on around her and she can react and join in. We love it. It’s all because Mia is able to use eye gaze technology, which allows her to communicate.

‘It’s revolutionary really,’ Margie said. ‘It’s an app installed on her computer screen. It has 16 cells, and each cell has a picture.

‘If Mia wants to say something she can gaze at a picture and choose what she would like to say.

‘If she’s feeling sad she can gaze at the sad face picture for a few seconds then it will vocalize she’s sad and open the next cell with 16 options of why she is sad. She might be feeling sick or tired, so it really helps us to understand her feelings and support her needs.’

Margie said Mia is quite a character and sassy and there are some things ‘really quite clever about her’ too.

‘With her eye-gaze Mia will tell you she’s bored; ask what you are doing; tell you you’re making too much noise and to stop and sometimes she will even ignore you!

‘I can walk into a room and say, ‘Hello Mia, how are you sweetheart,’ and she’ll look right past me. Then I say, ‘Fine, you’re not talking to me,’ and I start to walk away. Then she’ll look at me and smile and say, ‘I’m well.’ She has some attitude at times,’ Margie laughed.

As a part-time teacher working 4 days a week Margie says she is so grateful to the NDIS and all the supports and equipment Mia receives to help her life her best life.

‘I immigrated from Zimbabwe in Africa, a very poor country. It’s very different over there. You don’t get this sort of help,’ Margie said.

‘It has taught me to not take anything for granted and to be very grateful for the people and all the supports and services we have.

‘Mia is living a happy and fulfilling life. The NDIS has really helped her and it’s beautiful to see. She’s quite a smart little cookie and one to never be underestimated!’ Margie laughed.

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