Karina is stronger, happier and making friends, thanks to early intervention

Posted on:
2 July 2021

Like all young children Karina has a close relationship with her favourite snuggly toy.

But six-year-old Karina and her Fat-tailed Dunnart friend known as Edna share something particularly special. They are both missing the part of the brain that connects the left and right hemispheres—the corpus callosum.

Of course, Edna is a toy. But her real-life cousins in the wild share this distinct brain feature with young Karina.

For marsupials like the Fat-tailed Dunnart and other non-placental mammals, not having a corpus callosum doesn't seem to be a problem.

But for Karina and other children and adults like her, the rare congenital disorder known as Agenesis of the Corpus Callosum (ACC) can have a wide range of impacts from mild to severe disabilities.

For Karina, ACC affects her social and communication skills, strength, balance and coordination. And, as a result, her confidence.

"She was really dependent, always clingy," said Karina's mum, Hilary. "Other kids would be climbing at the park and she always wanted me to be with her and help her.

"She was sitting back and not doing things because she didn't have the strength. She was missing out on that experience and it was affecting her confidence and her friendships."

Karina is one of an estimated 6000 children and adults in Australia who have ACC or other Disorders of the Corpus Callosum (DCC).

She was diagnosed in-utero at 20 weeks' gestation, with the diagnosis confirmed when she was born.

"It's one of those conditions you don't know how it's going to present itself until further down the track," said Hilary. "There was a lot of worry, a lot of frantic internet searches."

For the first few years of Karina's life everything seemed fine. And then things changed.

"Karina was a good talker but we started noticing she was having trouble understanding what was being said to her and we had to repeat things. She loves ballet but we noticed her coordination was poor, and she was reluctant to do things. So we went to the doctor and looked for help."

Karina's doctors advised her parents to apply for the NDIS. Hilary says things have improved dramatically for Karina since she has been supported by the NDIS.

“She is stronger and has better balance,” she said. “She is finding it easier to communicate with other kids and make friends. She has grown a lot in her confidence and is becoming more independent and not as reliant on other people to do things for her.”

Karina has speech, occupational and physical therapies through an Early Childhood Early Intervention (ECEI) NDIS plan, which supports children with disabilities under the age of seven.

“I feel so privileged to live in a country where there is this kind of early intervention and to know Karina will be able to live a relatively independent life,” said Hilary. “It has made such a difference to her and we are so happy to see her becoming more independent and making friends.”

ACC affects around 1 in 4000 people. Many people are diagnosed as adults, having lived with the disorder for years. Some people have overlapping conditions such as autism, epilepsy, hypertonia or cerebral palsy.

“Symptoms vary significantly in presentation and how much they affect people’s lives,” said Maree Maxfield, secretary of AusDoCC, a national peer support group for Australian families, run by volunteers.

“People with these disorders are often isolated and bullied,” she said. “Many people have problems maintaining relationships and employment. They are often misunderstood.”

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