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Being born with a life-threatening genetic condition hasn’t stopped 20-year-old Jaden Dennis-Marler from shining bright, becoming an author and events planner.

With support from parents Tanya Dennis and David Marler, the NDIS participant is living his best life, but it hasn’t been without challenges.

'When Jaden was born in 2002, we didn’t know he had a disability,' Tanya, said.

When Jaden was 3 weeks old, he began to choke, Tanya says.

Jaden was rushed to hospital and placed in an induced coma.

'Throughout the early years, Jaden was very sick,' Tanya said.

'He would go blue and his larynx would not work due to his seizures.

'This would happen up to 8 times a day.

'But he was a fighter and I never gave up on him.'

At 3 months old, Jaden had been diagnosed with a rare genetic disorder called 1p36 deletion syndrome.

It affects up to 1 in 10,000 newborns.

Apart from the seizures, which are controlled through medication, Jaden cannot walk or talk, has scoliosis and a serious heart condition.

He is also hearing and vision impaired.

Jaden lives with his parents in Logan, south of Brisbane, in a purpose-built house with access to a range of NDIS supports.

These include a customised wheelchair, vehicle modifications, an all-terrain buggy, 5 support workers, consumables such as continence aids, physiotherapy, music and art therapy, as well as domestic help.

'The best thing that’s happened since Jaden became an NDIS participant is that David and I can now close our eyes and go to sleep,' Tanya said.

'Before the NDIS, David and I did everything.

'Jaden needed monitoring around the clock because of the risk of seizures and choking.

'We both had to put our careers on hold.

'We had to beg for donations because Jaden’s medical equipment was expensive.

'It was hard, but our main objective was keeping our child alive.'

With family backing and NDIS supports in place, Jaden has become the inspiration behind an events company catering for people with disability and a co-author of a children’s eBook series.

In 2021, Tanya, Vito Scandurra and Gina Chapman started MyCoolEVENTS, which organises social outings such as concerts, discos and cinema visits for NDIS participants.

'People like Jaden can’t go to a nightclub,' Tanya said.

'So, we brought the nightclub to him.

'His support workers and I help Jaden create events that cater to people with profound disabilities.'

Tanya says up to 60 people attend the events.

Jaden is also the star of an interactive children’s series about a boy living with a severe disability and his companion dog.

The Adventures of Benki Boo, now in its fourth series, is co-written by Jaden, Tanya and online mentor Vito.

It’s available on 45 online platforms, including Google Play Books and Apple Books.

'It tells a story about an alien that morphs into a dog to experience life on Earth,' Tanya said.

'Benki Boo finds this human who can’t walk or talk but they communicate telepathically.

'I write the content, Jaden and his dog star in the stories and Vito is the technical genius.'

Despite their successes, the family is taking it one step at a time, knowing how fragile life can be.

'We don’t look to the future, we just live in the now, because now it’s important to love and to shine.

'Our love for Jaden is so enormous.

'He continues to thrive thanks to the NDIS and his family.

'Jaden deserves the best in life.

'With the right supports, you can achieve anything.'

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