



## Daelle: About Me

My name is Daelle Isabel Bunker and I am 22 years old. I live in two loving families, with my Mum at her place, and with my Dad and Stepmum and brother and sister at my Dad's place. I spend half my time in each house and have done this since I was 4 years old. My older brother, Ashely, is 25, and my younger sister, Lorelei, is 13. My sister lives with me when I am at my Dad's house. Both my homes have lots of pets, I have dogs and cats, even a lizard!

I am not able to tell people what I am thinking, what I like and don't like, why I am happy or sad, when I am hungry or thirsty, if I am too hot or cold, or if I have hurt myself or been hurt by someone else. I have many times during each day when I am unable to participate in my life because of seizures. I do love to be part of everything that is going on at my homes, and when I'm out and about. I like to spend my time with people I love and who love me. I have had lots of challenges but still have a joy-filled heart and am often smiling and laughing when I am able to. When I am feeling good, I am a happy, fun-loving person who has big enthusiasms for the things and people I love. I always keep trying hard when I am able to and can be very determined.

I spend a lot of my time with my family, and since I first had an NDIS Plan three years ago I also spend time with formal support workers who help me live my independent life. My staff help me do gardening, cooking, art, shopping, and spending time with my friends. I also go to hydrotherapy, have exercise physiology, and do lots of community activities like art, gardening, music, going to the library, visiting gardens, bushwalking, going to the beach, and hanging out with my friends.

I need help with all my activities of daily living and most basic levels of care and am unable to care for myself at all. I need help with eating and drinking, all my physical care, cleaning my teeth, doing my hair, having a shower, getting dressed, and toileting. I use a wheelchair to get around and need support to use it. I need support to be mobile at home and in the community. I can't walk or stand



unsupported or push/control my chair independently. I can't communicate my choices or control my own life and activities. I have a lot of seizures and this interferes with my enjoyment of life and what I can do day to day. This also means my current capacities will decline over time, as my seizures damage my brain and take more of my abilities away. But when I feel good I have a lot of joy in life and share that with everyone around me.

My Dad bought me a wheelchair accessible car when I turned 16, and that means I can get out and about safely in my wheelchair and car with my family and my staff. I use my car to help me be independent and to help my family and staff care for me. When I feel well and am not impaired by seizures, my family think my favourite things to do include going for a drive in my car with the windows down and music playing; spending time with my family and my pets; seeing my grandparents;

doing art; going out and about to the movies or a café; going for a swim; wheeling outside at parks and going bushwalking because I love the outdoors; visiting the beach, gardens and galleries; and watching TV shows like Bananas in Pyjamas, Elmo, Play School, and Go Jetters. I will play with my dolls and have favourite bears and soft toys. With help, I can play and do therapy on my iPad and use my switch toys, especially my talking Cookie Monster which makes me laugh. I enjoy looking at books and having books read to me, especially books about babies!

I enjoy art with my friends. This year I started a small business making and selling decorated plant pots at a local market. We are also going to make art prints, t shirts and mugs to sell at markets and online. My staff and family help me be visible in everyday life by doing this with me, and I love all the different ways to make art that they come up with.

My family and my support workers also run my social media accounts which are about me and my life, and my new small business. You can check me out at:

- **Facebook:** Daelle's Adventures [www.facebook.com/groups/562689441110766/](https://www.facebook.com/groups/562689441110766/)
- **Instagram:** @dallebot and @snaellegarden
- **TikTok:** @dallebot

This is a way for me to be visible and participate in online communities, to reach other people and share my story and everyday life.

What's most important to me and my family is my safety and quality of care, that I am well looked after and not at risk of harm, that I feel loved and cared for, and that everything I need to stay alive day to day is done in a caring way with my best interests at heart and respect for me as a person. I am vulnerable to the world, that will pass me by if strong and caring people are not supporting me and advocating for my rights as a human being. I am person who matters to the world. I am very loved and deserve a life filled with love, joy and happiness. I deserve to be visible in the world, just like everyone else, and to live a wonderful, ordinary, life.



*Daelle at the local markets selling her art*

## About Daelle

Daelle is a 22-year-old woman who lives between two homes with her families: her Dad and Step Mum's (David and Michelle) and her Mum's (Wendy). Daelle spends a week at each home and swaps over on Fridays, and has done this since she was 4, for over 17 years. Daelle has an older brother, Ashley, who is 25, and a younger sister, Lorelei (13), who she lives with at her Dad's.



Daelle was born with Pachygyria, which is a congenital brain malformation affecting the cerebral cortex. Pachygyria is a form of Lissencephaly, which means "smooth brain." Genetic testing showed Daelle has the LIS1 gene.<sup>1</sup> Pachygyria affects how the cerebral cortex, or the "thinking" part of the brain, is formed. Daelle's cognitive processing, all the electrical messages to her brain and how they are processed, is affected: how she moves, how she sees, how she talks, and how she thinks.

Daelle, like most people with Pachygyria, has Cerebral Palsy. She has Quadriplegic (all four limbs affected) Athetoid/Mixed (fluctuating tone) Cerebral Palsy, at GMFCS Level V.<sup>2</sup> She has poor gross and fine motor control, and is MACS Level V,<sup>3</sup> is unable to walk or stand independently, and uses a wheelchair for mobility. She can't sit to stand by herself, reposition herself, or maintain a seated position in an unsupported chair. She is also medically incontinent. Daelle has Cortical Vision Impairment caused by sensory integration difficulties due to her brain malformation.<sup>4</sup>

Daelle has developed poor bone density due to long term wheelchair and anti-epileptic use. She has hip migration issues and had major surgery to reposition her hips and legs due to her Cerebral Palsy in 2012. She has broken a bone due to seizures and is at risk of further breaks.

Daelle has severe, refractory epilepsy: her seizures are not controlled by medication. She has several major seizures a week (tonic clonic, or atonic), and multiple small seizures a day (complex partial, gelastic, or absence). She is on four types of medication for epilepsy. Her seizures are a risk to her life, she may lose her airway, and she is high risk for SUDEP (Sudden Unexplained Death from Epilepsy), particularly overnight, and requires video and active monitoring. Daelle requires constant supervision and cannot be left alone. Her seizures have caused further damage to her brain which has reduced her capacities, and they will continue to cause damage and further deterioration.

Daelle has profound intellectual disability. She has no functional communication and cannot reliably express preferences or use verbal communication to express her choices (CFCS Level V).<sup>5</sup> She has some single words but does not use them to communicate her needs and choices. She is unable to read and write. Daelle can't feed herself, dress herself, and is totally dependent on others for all her basic needs and activities. Her basic activities requires at minimum "hand over hand" facilitation, and she needs attendant care for all her activities of daily life. Without someone doing Daelle's basic care, like feeding her and giving her water, Daelle would die.

Daelle completed Grade 12 at Mount Ommaney Special School in 2016, she did all her schooling in the Special School system. Since leaving school she has a full active life including swimming and workouts, bushwalking, gardening, art, and a range of community activities facilitated by her family and formal supports. She recently started a micro enterprise making and selling art.

<sup>1</sup> <https://www.ncbi.nlm.nih.gov/books/NBK5189/> outlines the LIS1 gene.

<sup>2</sup> <https://research.cerebralpalsy.org.au/what-is-cerebral-palsy/severity-of-cerebral-palsy/>

<sup>3</sup> <https://research.cerebralpalsy.org.au/what-is-cerebral-palsy/severity-of-cerebral-palsy/manual-ability-classification-system/>

<sup>4</sup> [https://aapos.org/terms/conditions/40&q=cortical+visual+impairment&ei=bve3T\\_PCF-250QXld3QBw&sa=X&ct=res&resnum=8&ved=0CC4QFjAH](https://aapos.org/terms/conditions/40&q=cortical+visual+impairment&ei=bve3T_PCF-250QXld3QBw&sa=X&ct=res&resnum=8&ved=0CC4QFjAH) for a description of CVI.

<sup>5</sup> <https://research.cerebralpalsy.org.au/what-is-cerebral-palsy/severity-of-cerebral-palsy/communication-function-classification-system-cfcs/>