

family services



Caring for the whole family

Like many boys his age, seven-year-old Archie Preston enjoys riding his bicycle, running around the backyard of his family home and going to the beach and swimming pool.

You might say that there is nothing unusual about this story, until you learn that Archie was born with a rare genetic condition and was diagnosed with an inoperable tumour when he was five years old.

Archie is mobile, but he is not able to talk and requires one-on-one care to meet his daily needs. His future is uncertain. This places great emotional and physical pressures on his parents Carley and Nathanael and Archie's four-year-old sister Cleo.

Very Special Kids helps lighten the load for the Prestons by offering emotional support, advocating on behalf of the family and providing a trained home volunteer to support Cleo. Access to respite care for Archie at Very Special Kids House also gives the family a much-needed break.

◀ Carley, Cleo, Nathanael and Archie Preston spending time together at Very Special Kids



▲ Nathanael Preston at the pool with Archie

Sadly for parents Carley and Nathanael Preston, Archie was unwell from the day he was born. But it was the second diagnosis a number of years after the original genetic condition that further added to the family's already challenging circumstances.

"When Archie was diagnosed with the genetic condition, the doctors said that he might not talk or walk. But we worked really hard and Archie learned how to walk. He had come such a long way. But then to get the tumour diagnosis on top of that – it was just a knockout blow," Carley said.

The uncertainty of whether the tumour will grow and how it could impact Archie is something that causes Carley and Nat great concern. Angela, their Family Support Worker, provides emotional support and counselling during these difficult times.

Angela said that an important role she has with the family is to "provide a listening ear about the ongoing grief and uncertainty they live with in relation to Archie's diagnosis. I am also someone they can chat to about the everyday pressures of caring for Archie and Cleo."

As well as providing emotional support, Carley highlighted how Very Special Kids also advocates on their behalf to access services and make arrangements to accommodate the special needs of their family.

"Angela is amazing and always has our needs at the centre of everything she does. She always comes up with good ideas and is a real supporter for us. She is always there if I need her and her experience really helps."

"As an example, when I was in hospital with Archie and I missed the cut-off date to have Cleo enrolled in our local three-year-old kindergarten,

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 "Before Very Special Kids, we couldn't have even contemplated having a holiday with Cleo, but we recently went away for ten days and took Cleo on a plane for the first time."

Angela wrote the kindergarten a letter to advocate on our behalf for special consideration based on our family's situation. Cleo ended up getting a place and that was the best news. I don't think that would have happened without Angela. Even though that had nothing to do with Archie's care directly, Very Special Kids helped us with such an important issue for our family," Carley said.

Carley and Nat are aware that the amount of care and attention

they have to give to Archie has an impact on Cleo. Nat explains that Very Special Kids' home volunteer program helps in this area.

"Kristi is our home volunteer and she has been so good for everyone in the family, especially Cleo. It's great that Kristi spends so much time with her, as Archie has constantly had all these people attending to him and his needs. But Kristi is Cleo's special friend and it's Cleo's time for attention – that is so important. Kristi is really good with her and she

is always open to all of Cleo's crazy ideas," Nat said.

"We also hope that Cleo will want to be involved in the Sibling Program when she reaches primary school age, as it would be great for her to meet other siblings that are in a similar situation to her," Nat said.

When Carley mentions the importance of having a break and spending time focusing on Cleo, she highlights the significant role Very Special Kids House plays with providing respite for Archie.

"Before Very Special Kids, we couldn't have even contemplated having a holiday with Cleo, but we recently went away for ten days and took Cleo on a plane for the first time."

"We feel really confident and comfortable that when Archie is at the House, he is in the very best of care. And he loves it at the House. He gets so excited when we walk through the door and he jumps up and down and takes off exploring," she said.

For the Prestons, the most valuable aspect of Very Special Kids is the peace of mind in knowing that they have support if they need it.

"I think the biggest thing for me is knowing that there is experienced support to call on in an emergency. If something major or unexpected happens in our life, we know that Very Special Kids will be there to support us," Nat concluded.



Family Services

825
 FAMILIES
 SUPPORTED
 BY VERY
 SPECIAL KIDS

111
 NEW
 FAMILIES

47
 CHILDREN
 DIED

211
 TRAINED
 VOLUNTEERS

17
 FAMILY
 SUPPORT
 WORKERS

290
 ATTENDEES
 AT 11
 SIBLING &
 ADOLESCENT
 ACTIVITIES

680
 ATTENDEES
 AT 52
 REGIONAL
 ACTIVITIES
 FOR FAMILIES