

A close-up photograph of a woman with blonde hair, wearing a white top and a small hoop earring, leaning over a baby in a hospital bed. She is kissing the baby on the forehead. The baby is lying in a bed with white metal bars, wearing a blue hospital gown and has clear nasal cannula tubes in their nostrils. The baby's eyes are closed. A green blanket is pulled up to the baby's chest. To the left of the baby, there are several stuffed animals, including a large orange one and a smaller white one. The background is softly blurred, showing the white bars of the hospital bed and a window with light coming through.

very special kids house

Liam's lifetime

While Anthony and Danielle Briglia were coming to terms with the devastating news that their 15-month-old son Liam would not have much longer to live, they were asked to consider where they wanted him to be when he died.

During a time of confusion and stress when nothing seemed to make sense, this decision was an easy one to make. In what Danielle describes as "the best choice we made", Liam came to Very Special Kids House, where he peacefully died.

Very Special Kids House in Malvern is a purpose-built children's hospice where families can access planned and emergency respite, as well as end-of-life care. It was Australia's first, and remains Victoria's only, children's hospice. Providing 24 hour specialist nursing care, the House is a home-away-from-home that features bright lounge areas, soft-play areas, gardens, a music therapy room, a multi-sensory room and fun-filled school holiday and weekend activities.

◀ Danielle Briglia gives her son Liam a loving kiss



▲ Anthony, Jacob and Danielle Briglia enjoy the playground at Very Special Kids House

When Liam was born, Anthony and Danielle knew that there was something wrong, but they could not have imagined how severe his condition would become. Danielle explains that while Liam was breastfeeding, he wasn't sleeping very well and was crying a lot.

"Our GP referred us to a specialist and then four days later Liam had his first seizure. After that we went to the Austin Hospital and he kept having seizures, so they rushed us over to the Royal Children's Hospital. Originally, they thought it might have been epilepsy, but the more specialists we saw, the more they became unsure."

"They performed an EEG test on his brain that showed Liam had a large amount of seizure activity, but they still didn't really know exactly what was wrong. That was really hard for us – we were in shock and didn't know how we could help our little man. Watching him in a cot and not being able to cuddle him was horrific," Danielle said.

While doctors and specialists were trying to find a diagnosis for Liam, Anthony and Danielle were also caring for their eldest son Jacob, who was two years old at the time.

"It was a very stressful time. We were hoping that there would eventually be some good news, but it just didn't

come. We weren't coping well at all and that's when the Royal Children's Hospital suggested that we contact Very Special Kids," Anthony said.

Very Special Kids supported the Briglia family over the coming months as Liam's health deteriorated until they reached the heartbreaking realisation that his life was coming to an end.

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"I wanted Liam to come to Very Special Kids House. For me, that was the best choice we made. It was a nice way to say goodbye to Liam."

"When the Victorian Paediatric Palliative Care Program called us to ask what we would like to do, I said that I wanted Liam to come to Very Special Kids House. For me, that was the best choice we made. It kind of feels like a home and it was

much nicer than being in a hospital," Danielle said.

"The support we received at Very Special Kids House was amazing and not having all the craziness of a hospital around you was so much better. It was a nice way to say goodbye to Liam."

"There was one staff member in particular who would sit with me and make me toasted sandwiches and cups of tea. She was fantastic and supported me in a way that you just don't get at the hospital."

"We were able to personalise Liam's room – we had his pillow and all the things I wanted him to have with him. I also really loved how the staff always took Liam out into the main room with all the other children, so he wasn't left in his room all alone."

"When the time came, Liam was taken to the Special Room and we sat by his side waiting for him to pass. The staff were really respectful and gave us the right amount of space and support – they are highly experienced in these situations," Danielle said.

During the last days of Liam's life, Anthony and Danielle stayed in the parent accommodation next door to Very Special Kids House, which provides families a comfortable environment that allows them to be close to their child.

The Briglia family continues to be supported by their Family Support Team worker Briana and they are regular visitors to the House and participants in Very Special Kids events.

"We have stayed in contact regularly since. I think it's good for Jacob to have that contact and understand what was wrong with Liam. It has helped him a lot and he sees Very Special Kids as a special place, not a bad place where Liam passed away. He loves the piggy banks, the playground and humpty dumpty. He also has a wonderful relationship with Briana – she is great with him," Danielle said.

In addition to end-of-life care, Very Special Kids House provides families with planned and emergency respite care. The House makes it possible for families to have a break, go out for dinner, on a holiday, or just go home and catch up on the sleep they so desperately need.

During a respite stay at Very Special Kids House, the hospice team of doctors, nurses, carers and volunteers become familiar with a child's care needs and work to a routine the child knows at home, which provides parents the opportunity to relax.



Very Special Kids House

1706 BED NIGHTS OF CARE

ADMISSIONS **343**

374 MUSIC THERAPY SESSIONS

COST PER BED NIGHT **\$1000**

174 FAMILIES USED THE HOUSE

EACH YEAR TO OPERATE HOUSE **\$3M**