

Jeremy's big hug says 'Thanks, Mum and Dad'

By DAVID HUDLESTON

Jeremy Netherway's eyes lit up and he gave his mum a huge hug when he moved into his new Mt Claremont house.

It was a hug his mother Nicki had never experienced before from her profoundly disabled 13-year-old son.

"He gave me this amazing hug – it literally curled right around me and I am thinking, that's amazing, it's a really nice hug," she said.

"Then he did it again – he did it five times and he has never done that before.

"He has never been able to – it was a really unique experience and I just link it to the fact that he was happy."

Jeremy contracted meningitis at the age of 10 months. Misdiagnosis in hospital and his subsequent deterioration led to loss of movement, except for a little remaining in his right arm, loss of hearing (he now has cochlear implants) and loss of vision, which has since improved.

He also has cerebral palsy and epilepsy and has poor control of his body temperature (he is often hypothermic).

His parents, Nicki (46) and Peter (51), both left work to look after him full-time, in a small, inadequate house next door to the block on which they finally built Jeremy's house.

Compensation awarded to Jeremy in 2008 made the prospect of a purpose-built house possible, but the challenges were daunting.



Designer Dean Bell watches as Nicki and Peter Netherway lift Jeremy in his sling.

The house was built around Jeremy's pressing need for a family home that would accommodate his long-term requirements for 24-hour care and vast array of special equipment.

Its design had to accommodate Jeremy's increasingly demanding physical and emotional needs, his integration into the heart of the family home, and

his parents' drive to provide him and his three school-age siblings with important health-related benefits and surroundings that would bring joy, some degree of ease, and economies of operation.

The home is built with a passive solar design and according to sustainability principles. It features solar power and water heating, rainwater and

grey water collection tanks, glass walls on the north side to capture the winter sun and warmth-absorbing black floor tiles in the living areas, while cross-ventilation eliminates the need for air-conditioning.

Dean Bell, from Cross+Design, incorporated all Nicki and Peter's ideas into the design.

But the spacious, remarkable house – a benchmark in design

for people with disabilities and their families – could not have been built without the generosity of Jay and Ron Mangano, of Devrite Homes of Distinction, and their construction and supply team.

When building costs became an issue they approached their suppliers and asked for their help.

"We had a budget and we didn't think we would make the budget we had been set," Peter said.

"What got us over the line was Ron and Jay's extra work with their suppliers.

"We knew we were pushing the boundaries."

Jay said the steeply sloping block required a lot of retaining, while design and construction changes to accommodate Jeremy's special needs and his parents' green requirements were extensive and expensive.

Then there were the special features to help make Jeremy's life more bearable and his family's life physically easier.

A hoist system was installed so Jeremy, who is becoming more difficult to lift as he grows, can be hoisted into a sling attached to a ceiling track and taken from his bedroom to his daily bath and his physiotherapy area.

The ceilings had to be reinforced to take the tracking system, imported from the US. The same hoist is being installed in the new Fiona Stanley Hospital in Murdoch.

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In the west-facing backyard, a huge 80-year-old marri tree was retained. Jeremy has poor head control and is tilted back in his wheelchair, so Nicki and Peter believed it would stimulate Jeremy if he could be wheeled on to the verandah and watch the sky and the leaves of their big tree dancing in the breeze.

So a thick roof window was built.

A small pool was installed off the deck leading from his bathroom, so he could be wheeled in his bath trolley and lowered into the pool.

"Being in water like this is one of his few delights in a life that is fraught with difficulty day after day," Nicki said.

Jay said: "It was clear that everything that was going to make a difference to Jeremy's life was going to be more expensive than anticipated, but by then we had

been drawn into the Netherways' lives and Jeremy's future – and we felt we just had to help them achieve their dream.

"We contacted our suppliers and asked if they could help us keep the costs down by providing discounts or whatever they could, for Jeremy's sake.

"We were thrilled by the response from an industry that, itself, is feeling the pinch and their efforts have meant that we could deliver the home that really will make a difference to Jeremy's life and that of his fantastic family."

That difference is already being felt.

"Since moving here we haven't had the heater on during the day," Nicki said.

"In our old house we had to have the heater on all the time because Jeremy can't control his temperature. There is a huge cost associated with that."