One minute we had been watching our child moving around on the monitor. The next, we were being told we would never see her grow up.
Like most new parents, Hannah and Ian Hicks couldn’t wait to go for their 20-week scan. But all that excitement turned to anxiety when the midwife went to fetch the doctor.

They were told the most devastating news any parent can hear – their unborn daughter had a condition that meant it was very likely she would die in childhood.

“We left the hospital feeling like our world had fallen apart,” said Hannah.

“One minute we had been watching our child moving around on the monitor. The next, we were being told we would never see her grow up.”

20-month-old Alice was born with hydranencephaly, a central nervous disorder. The condition means Alice’s brain isn’t fully formed and she is sadly not expected to reach adulthood. Her family was forced to prepare for the worst as she spent her first 15 days fighting for her life in the neonatal unit at the University Hospital of Wales.

“As it became increasingly clear the doctors could do nothing more to help her, they suggested we took her for end-of-life care at Ty Hafan,” said Ian.

“Being told by our doctors that we would have to go to Ty Hafan felt like the end, but it turned out to be a new beginning.”

After the fear and devastation of the previous weeks, it was at Ty Hafan that the couple finally found some hope and happiness.

Hannah said: “What we found at Ty Hafan was something truly special – a place filled with laughter and smiles and love. We knew straight away that this was where we wanted to be.”

On the first day at Ty Hafan, Alice’s grandfather had the chance to hold her for the first time. He hadn’t been able to hold Alice when she was in hospital, because she had been too poorly.

“As he cuddled his tiny granddaughter in his arms, he told us that his life felt complete. It was such a special moment for the whole family,” said Hannah.

“Thankfully, Alice pulled through those early weeks and is now enjoying spending time at their home in Cardiff.”

“There are so many ways Ty Hafan continues to be there for our family,” said Ian.

“From the visits and phone calls from our family support practitioner, Hayley, to the short breaks we have at the hospice, they help make sure every moment we have with Alice is spent creating memories that will last forever. We know that when the time comes, and Alice reaches the end of her life, they will support us through that too.”

Ty Hafan takes its support to wherever it is needed: at home, at school or in hospital. We do this completely free of charge for families in Wales that need us. Please help us continue to be there for life-limited children and their families, so they can make the most of the precious time they have left together.

For more information visit www.tyhafan.org or call 029 2053 2199.