

Emma's Story



Liam, Ethan and family at an ECHO event.

Liam Goulding was born in St Thomas's hospital on 1st December 2008. He was welcomed into the world by proud and loving parents Emma and Bruce and excited older brother, Ethan, who was looking forward to having a younger brother to play with and share adventures.

Sadly, as much as his arrival was joyful it was also an extremely anxious time, as little Liam was born with the complex congenital heart condition called Transposition of the Great Arteries, and his birth was just the beginning of his fight for survival.

A routine antenatal check at 21 weeks with an experienced Sonographer at Lister hospital, led to follow up review appointments in London, at which Emma and Bruce were told that their unborn child had a life threatening heart condition, and from that moment the family plunged into their worst nightmare: that their little boy's life was at risk, and that he would need urgent, critical care from the moment he was born.

Mum Emma recalls learning of the diagnosis, and the moment that changed her life forever.

Hearing those words and knowing that Liam was, and would be so ill, was gut-wrenching. I was just in complete shock.



Liam in hospital.

The remainder of the pregnancy was, as to be expected, a far more anxious and unsettling time for the Goulding family, but with support from ECHO and the medical team around them, stresses were able to be managed and alleviated somewhat, as Emma explains.

Very soon after we learnt of Liam's diagnosis, we were introduced to the charity ECHO, and we were brilliantly supported through their amazing network. Because of ECHO, we never felt alone.

"We were introduced to a number of other people who had been given neonatal diagnoses with their children, similar to ours, and we formed a little neonatal heart group. The support I drew from others in the same boat was tremendous, and through ECHO we were also connected with families who had been in similar positions to ours and whose children were now thriving.

ECHO helped to join up a lot of the very overwhelming dots in the understanding

of and planning for Liam's early interventions so we were as prepared as we could be for the treatment he needed to receive once he got here."

During Liam's surgery and recovery, his parents lived at the Ronald MacDonald House, connected with the hospital. Older brother Ethan was able to experience as little disruption as possible to his usual routine - something which is really important for young siblings; he lived during the week with his nan and grandad, and joined his mum, dad and brother at the weekends where they all stayed together at the Ronald MacDonald house.

Mum Emma says: *"ECHO provided constant support and advocacy and helped to ensure our family maintained as much normality as possible for our older son, Ethan. As a family we were able to be together at the Ronald McDonald House, which was vitally important to all of us. ECHO helped hugely in helping us to sustain and maintain a family life in the early days when things were the darkest...ECHO saw us as a family, and gave us support as a family, and that has made all the difference to all of us"*.

"It was confusing and hard for his brother. One day Ethan came to visit Liam in hospital. He didn't understand why he was so ill and he tried to pick him up off his bed and carry him home."

ECHO remains close to the Gouldings, and continues to provide support along the way at each milestone in Liam's life, and at the times where extra help and support is often needed in navigating heart health and challenges.

When Liam started school, it was understandably a difficult time for his parents, who were worried about ensuring Liam had the care and support he might need and protection should anything happen. His school were really understanding and open to learning about his condition, and with ECHO's support, guidance and expert [information](#), together his family and school put care plans in place and created a strong, safe and reassuring environment for Liam.



Liam and Ethan.

Over the years, the Gouldings have become a real part of ECHO's community, meeting other families, taking part in various ECHO activities and events, and continue to access services and support through the charity, which helps not just with the big challenges, but with the every day anxieties and concerns too.

"We really look forward to coming to ECHO events - it is so important and over the years we have been to most Christmas parties and as a family we can meet other people experiencing similar situations, chat to other parents, and give the kids a really special time. As a family we have made many very special memories at ECHO events."

Liam had the Arterial Switch operation and today he enjoys living life as any regular ten year old boy

would. He is part of his school's running club and a keen and active member of the local Cubs. He plays football every week and is a real live-wire. He is very close with his brother Ethan, and they love to play together and go on those adventures that Ethan dreamed about. Life is stable, and Liam is happy and well, and the family are reassured that ECHO will always be with them and there for them, should they ever need.

"Liam is doing really well. It is sometimes hard to see him as someone with a very serious heart condition."

"He is stable and as a family we are no longer living in such trauma, but it is never far from our minds. I know that ECHO will be with us for life, throughout life, and knowing that Liam can be part of their [Teen Club](#) soon gives me such gratitude."

ECHO have support for every part of life's journey. Life with a congenital heart condition was a total unknown to us and was a terrifying concept, but with ECHO's constant care and support, we know we are not alone".

ECHO would like to thank the Goulding family for sharing their story, and for all their support.

In 2014, Liam's dad Bruce, a keen runner, ran the London Marathon for ECHO, raising over £7000, and the family continue to do lots of community fundraising as well. [Every penny raised](#) goes right back into helping children like Liam, and their families.

Written by Victoria Goldsmith, speaking to Emma Goulding.