

**NHSBT Board Meeting  
27 September 2022**

**A Child Waiting for a Heart Transplant: The Story of Grace and her family.**

Little Grace was born in 2019. A miracle child to parents Becci and Daz, Grace was the result of 10 years of trying to conceive before starting IVF treatment and alongside her big brother Josh completed her family. The family at that time lived in Dudley and Grace was born in the local hospital. Initially considered a healthy baby the first concerns for Grace were raised at 24hrs old, as she was checked over, she suddenly went grey. Following transfer to Birmingham Children's Hospital Grace was diagnosed with a mild impairment of her left ventricle function, Grace was an inpatient for 2 weeks before being allowed home with her family.

Grace was well until February 2020 when her parents noticed her breathing was a little more laboured. Diagnosed with mild bronchitis, Grace was given medication and sent home. A regular echocardiogram appointment a few days later showed that her heart was enlarged, she was diagnosed with dilated cardiomyopathy, Grace was admitted as an inpatient for 2 weeks before being sent home with large numbers of medications to help her condition. Home for 3 precious weeks, her parents' noticed Grace wasn't doing so well, they took her back to Birmingham Children's where her Oxygen levels were found to have dropped, while in the Hospital Grace suffered a cardiac arrest, the first of many through her journey, this was the start of an 863-day continuous hospital stay for her. Becci and Daz describe how they had to adapt to a new type of family life, they had to alternate between staying with Grace and providing a home life for her brother Josh, meeting as they swapped roles and sharing important updates in corridors and through brief snatched moments as they worked to care for both children. Just as this process could not have seemed it could be more challenging, the UK was rapidly approaching the first COVID-19 lockdown.

A heart transplant was first mentioned to the family in February 2020, but this initially was in the context that she may need a transplant but could also recover function. Unfortunately Grace became more unwell and in April she joined the Transplant Waiting List. By this point Grace was critical, she was on a ventilator, on dialysis and had suffered a bleed on the brain. The family were advised to 'make memories' with Grace as her survival was far from certain. It was at this point that the potential use of the Berlin Heart at Newcastle was mentioned, but the team were unsure if Grace would be accepted for the device. Her case was shared with the Newcastle team and

the family were told that Grace had been accepted for the Berlin Heart, meaning that she would need to be transferred up to the Northeast for her ongoing care. The transfer was made and in May 2020 little Grace was placed on the Berlin Heart.

Because of COVID-19 and lockdown the move to Newcastle was even more complex than usual. There were no hotels, no visitors were allowed except for one parent and travel was almost impossible. Initially Becci and Daz both stayed in Newcastle, staying at the Sick Children's Trust in the hospital grounds for the duration while brother Josh was cared for by family in Dudley. It was vital that Josh was cared for by his loving parents and therefore Daz started to alternate his time between the children while Becci remained by Grace's side. Becci describes the surreal nature of that time, the world seemed to be carrying on outside the hospital grounds, while inside Grace was on the ventilator, like sleeping beauty unaware that the world was moving without her.

Grace responded well to her Berlin Heart, her team were able to lower her sedation initially and then end her sedation and remove her from the ventilator as the Berlin Heart took the strain off her own heart, freeing her from her bed. Grace started eating and drinking and even began gaining weight. After months where brother and sister were separated, Josh was finally allowed to visit Grace for one hour a week, but other visitors were still prohibited. Grace was later transferred onto the Berlin Heart Active, making her the first child in the UK to be fitted with the device. The Berlin heart Active allowed her to be more mobile as her old Berlin heart machine only had 30 minutes battery life, severely limiting how far Grace could go before needing to be back on the Ward.



Becci and Daz got trained on the Berlin heart Active and were consequently able to take Grace out around the hospital grounds and even on a precious trip out to the park under the supervision of the expert Vad nurse where Grace saw ducks for the first time!

This freedom, allowing Grace to experience life away from Hospital, was very special for the whole family and Becci explained how their situation truly made you appreciate the little things in life that would have previously have been taken for granted

Life for Grace was reasonably stable until she developed a bad infection in October 2021. This saw her readmitted onto PICU for the first time, since having the Berlin heart fitted Grace got over the infection but then suffered a stroke which resulted in the loss of all movement in her right side. Fortunately Grace once again survived a real threat to her life and in the weeks and months ahead recovered her movement and started to learn to walk for a second time.

Winter 2021 the amazing staff at Freeman hospital arranged a visit to see Santa at Fenwick in Newcastle which was a magical moment for all of the family.

Spring 2022 the 'call' came on a rare night at home for Becci with Josh while Darren was at the hospital with Grace. The call came through at 4.30pm from the Newcastle Team saying they think they have a heart for Grace, Daz was in shock, he knew he needed to phone Becci but just sat there frozen to the spot! Before one of the nurses said you better go outside and give Becci a ring. Having spent so many months with Grace in hospital the family had moved to the Northeast to be together as much as possible, so Becci made the 20-minute journey to the hospital to be with her daughter. Once their final checks on both Grace and the prospective donor heart were completed and the transplant was confirmed. Grace went to surgery at 2am. Becci held it together until the moment Grace went into surgery, then she was swamped by a mix of emotions, thinking of the young donor, her daughter's health, the future and so much more. Daz and Becci stayed up all night. As Grace underwent 12 hours of surgery. When they first saw her post-op it was hard as she was back in the bed and on the ventilator. The next day Grace had a cardiac arrest as her new heart was in an unstable rhythm, but thankfully her condition stabilised quickly.

After a period of stable recovery Grace went into rejection and was put onto ECMO. Grace had plasma cell exchange treatment to reverse the rejection, and she started to improve and got off the ventilator. What followed was weeks with Grace in bed on oxygen, so when she did start to move she was very stiff and in pain. The family have been supported throughout by the excellent medical and nursing teams who had built a strong bond with Grace, her nurses are like an extended family of aunts for the little girl. As Grace improved her new heart was considered strong enough to work alone, as Grace returned to the ward from surgery, minus her Berlin heart, the nurses clapped and cheered her return. Grace was initially upset by the loss of her Berlin, something Daz and Becci had not expected, but she regained her mobility quickly and soon loved the freedom her transplant gave her. As Grace finally was able to go home, over 800 days after her arrival, the team formed a guard of honour to applaud their final walk, there were plenty of tears and great joy that Grace was going home.



Grace now is home and attends clinic weekly, she is enjoying home life, as are her entire family. Her transplanted heart is doing well. The family are eternally grateful to the donor and their remarkable, brave, and benevolent family, who, when faced with the loss of their beloved child, decided through the gift of organ donation to save another child.

**Author**

Grace's Parents; Daz and Becci. Supported by Lorraine Fahey, Business and Project Coordinator, OTDT.

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