CAPTURING THE PARENT VOICE
MATILDA'S STORY

My name is Rebecca Maher, and I've been invited to tell you about our beautiful daughter Matilda Quinn who died in 2015 at the age of 8 months.

Matilda was our first baby, and like all other first-time parents, my husband Brendan and I had no idea what was in store for us, but looked forward to muddling our way through parenthood. At my 20-week scan, just before Christmas 2014, we were given the devastating news that Matilda was going to be born with a very serious heart condition called hypoplastic left heart syndrome (HLHS). Our baby's life was going to be very different than the one we had imagined.

Our baby daughter was born on Monday 13 April 2015. We called her Matilda, which means 'strength in battle'. Matilda was transferred to Children's Health Ireland (CHI) at Crumlin within 1 hour of being born, and had her first open-heart surgery, the Norwood procedure, when she was just 3 days old. Matilda was very sick in the days following her surgery and there were times when we thought that her tiny heart was not strong enough to get her through, but she lived up to her name and made a speedy recovery. We brought her home on 1 May, when she was two and a half weeks old.

Matilda went from strength to strength in her first few months. She was back in CHI at Crumlin for regular check-ups, but gained weight steadily and did all the things a little baby should do. She was full of smiles, and she loved when we sang songs and read stories. She listened intently and almost seemed wiser than her years. She was a placid, happy baby girl who brought us so much joy.

Following her second scheduled heart surgery (the Glenn procedure) at the end of July, we brought Matilda home again, hoping for a 3-year break until her next major heart surgery was due. This was when her life was due to begin properly. Up until then, we had had to shelter Matilda so much until she was strong enough for that second surgery. Now we could start introducing her to more family and friends and more life experiences, bringing her out and about to enjoy life.

Sadly, Matilda became unwell about 10 days later and we brought her back to CHI at Crumlin, where she was admitted and treated for postoperative complications. Matilda had developed chylothorax, and she had two lung surgeries and several cardiac catheterisations over the next few months, but she gradually became more and more unwell.

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By then, Brendan had to go back to work, but I spent all my time in CHI at Crumlin with Matilda, reading her stories and singing her songs, and meeting musicians, play therapists, All-Ireland winning teams and other Irish celebrities who kindly took time out of their days to come and visit. Those visits mean the world to patients and their families, especially long-term patients whose lives are spent waiting for doctors' rounds, weekly meetings such as the Joint Cardiac Conference, and the results of tests and X-rays.

In early December, when Matilda was almost 8 months old, we met with her multidisciplinary team and talked about what lay ahead for Matilda. It was clear that she was a very sick little girl, her heart was failing, and she was not going to recover. On the advice of her medical team, we made the extremely difficult and devastating decision to withdraw the supports Matilda was on and let her go. Matilda passed away in our arms on 7 December 2015, aged almost 8 months old.

Losing a child is one of the most devastating things that can happen to a person and to a family unit. It has changed who I am entirely. Even more than 9 years later, the grief is not any less, I'm just better at carrying it. We are incredibly blessed to have three more children now, who know all about their big sister. She is regularly talked about in our house, and my son Leo sometimes calls on Matilda to guide him through tough tasks. We feel blessed to have been able to give someone else the chance to live a healthy life by donating Matilda's two tiny kidneys to a man in Leeds, which has brought us a lot of comfort.

Since Matilda passed away, we've received support from so many people, including trained professionals, family and friends. Anam Cara, which provides support groups for bereaved parents, has been instrumental in giving me hope that there is life after the loss of a child, and has allowed me to share common experiences with other bereaved parents. I've also been involved with the Health Service Executive's Organ Donation team in raising awareness of the importance of having the conversation, and with the Children's Health Foundation in raising funds for the Children's Heart Centre in CHI at Crumlin in memory of Matilda.

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If Matilda had been born 30 years earlier, we may have had much less time with our baby girl and she likely would have passed away in the first week of her life. Thanks to the huge investment in research into paediatric cardiac surgeries, Matilda was given a chance at life and we were given hope of a future with our baby girl. Although Matilda's story ended prematurely, many other children have gone on to live fulfilling lives because of this research, with the oldest surviving patient with HLHS now nearly 40 years old. The importance of research into all aspects of children's medical needs, possible treatments, and even their deaths cannot be understated in the effort to constantly improve outcomes and give sick children and their families the best chance at life.