

Demelza's **Festive** wishes

Demelza
Hospice Care for Children

On Christmas Eve last year, it was our festive wish to bring our daughter home so she could be surrounded by family and love.

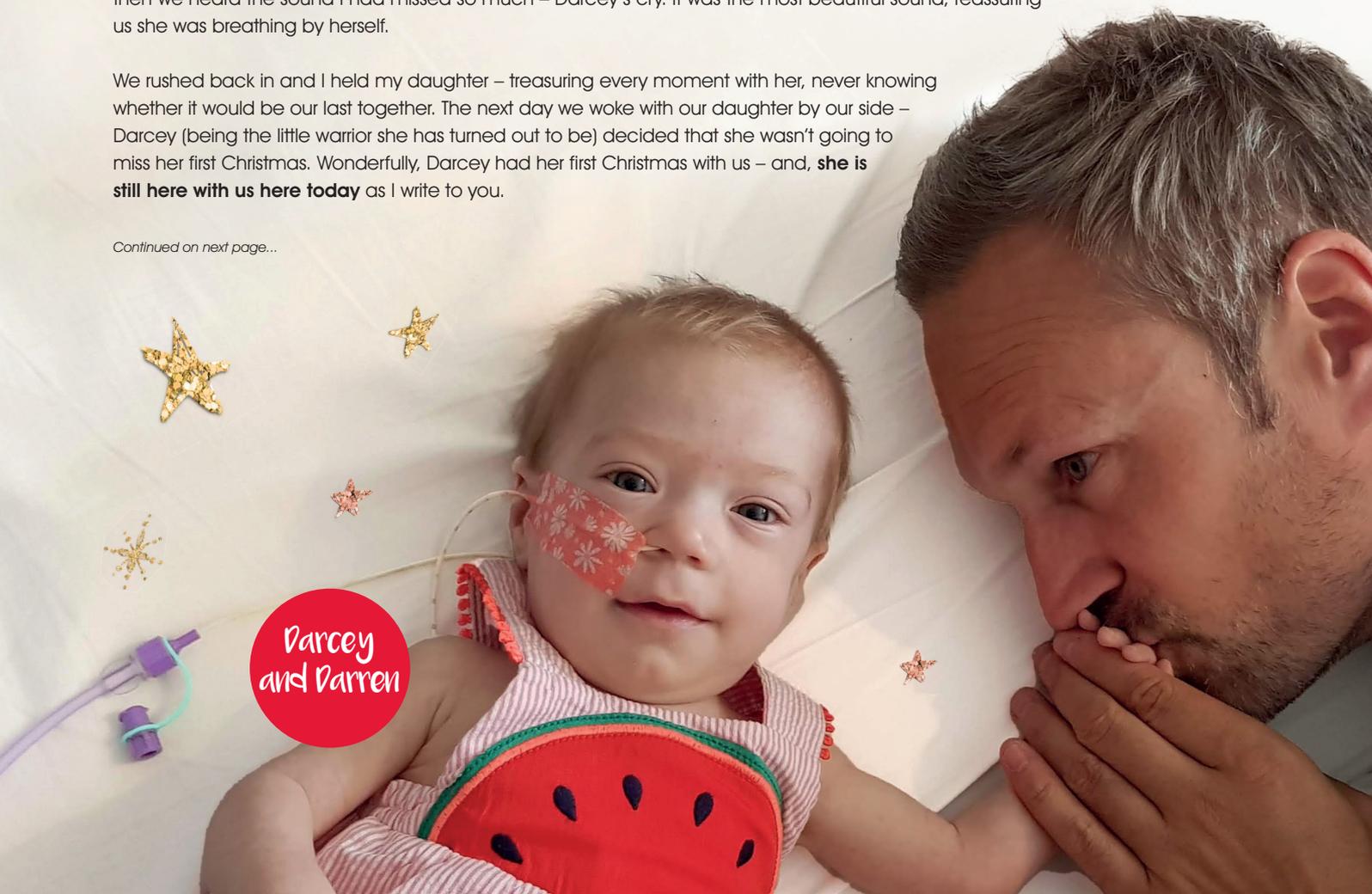
When I was 20 weeks pregnant, we were told that our baby would need heart surgery – but would hopefully go on to lead a normal life. Darcey was born in October 2020 – and at two months old, our little girl had already been through two major operations. It was such a difficult time and the added complications and restrictions of COVID-19 prevented us from being with her as a family as we so desperately wanted to. Sadly, and very unexpectedly, just before Christmas she started to struggle. We were given the devastating news from doctors that Darcey's heart could not be fixed.

Darcey was very fragile and we were told she could pass away at any moment. With a tube helping her to breathe, she just looked so poorly. Very quickly our thoughts turned to Archie, Darcey's four-year-old brother. How could we possibly break the news to him? Having only met his little sister once, he longed for her to come home whilst, of course, being very excited about Christmas! We desperately wanted to give Archie a happy memory of his sister and his new family and didn't want this Christmas and those that followed to be focused on sadness. And so, we decided we would bring Darcey home on Christmas Eve. Being together as a family at home for the first time would make Christmas Eve our special day to celebrate for years to come.

On Christmas Eve I travelled with Darcey and two wonderful intensive care nurses in a specialist ambulance. At home, we were introduced to more nurses including Lottie, our Demelza nurse. That day, Lottie helped us make all sorts of precious memories. She took clay impressions of Darcey's feet so we could remember how delicate they were. I remember that she laughed when she realised I had bought 10 kits! It was so comforting to have Darcey home for Christmas, with the chance to take lots of photos and have cuddles. After just a few hours, it was time for the nurses to remove Darcey's breathing tube. We had no idea whether she would breathe for herself or for how long. We kissed Darcey, left the room and waited anxiously. And then we heard the sound I had missed so much – Darcey's cry. It was the most beautiful sound, reassuring us she was breathing by herself.

We rushed back in and I held my daughter – treasuring every moment with her, never knowing whether it would be our last together. The next day we woke with our daughter by our side – Darcey (being the little warrior she has turned out to be) decided that she wasn't going to miss her first Christmas. Wonderfully, Darcey had her first Christmas with us – and, **she is still here with us here today** as I write to you.

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**Darcey
and Darren**

It's October as I write this, and we have just celebrated Darcey's 1st birthday. We try to focus on positive moments – there are so many. But, we are also faced with many lows, including episodes when Darcey's body is under stress, causing her to pass out. In these moments, I have held her in my arms, unsure whether she will wake up again. There are times her breathing has been so bad I have tried to prepare myself for the worst.

Darcey needs constant care and medications to keep her comfortable. She breathes for herself but needs to receive a slow, steady flow of milk through a nasal tube via a pump. It can be fairly exhausting and the idea of 'sleep when your baby sleeps' is far from possible as I have to ensure she is receiving milk safely and give her medications throughout the day. Day or night we also need to try to prevent her from crying as this could place too much stress on her heart.

Darcey's smile and her character help us stay strong – as does the support from our friends and family. **But, due to Darcey's complex medical needs, there is so much they cannot help with. That's why the support we've been receiving from Demelza has been vital.**

Lottie is still our Demelza nurse. She is so wonderful, calm and knowledgeable and we can hand Darcey over to her without worry, knowing that she will care for our little girl as if she was her own. A home visit from Lottie means she takes over all of Darcey's care for a few short hours, enabling us to spend some quality time with Archie or get some much-needed rest.

Lottie has also helped us at Demelza's hospice, somewhere I never imagined I would need but did so when at the point of exhaustion. At Demelza, Darcey has always been lovingly and expertly cared for by the nurses whilst we've stayed in their special parent accommodation, giving us time to rest. On one of our visits, the nurses helped Darcey when she was very poorly. They made her smile just in time for my first Mother's Day with her. Darcey loves going to Demelza and for Archie, it has allowed him to explore his feelings through art therapy and play at such a difficult time. In fact, he keeps asking when we can go back!

Demelza has helped us through some of the worst moments of our journey, supporting us in so many ways. They continue to help us and are always a phone call away. Darcey is a bright, funny, cheeky little girl with an unbelievably infectious smile; but we know she will not live a long life. At any moment we may have to say goodbye to our beautiful girl.

The reason I am sharing our story with you is so you can hopefully understand how utterly life-changing Demelza's care really is – the care you make possible when you support them. Your fundraising efforts and the donations you give made it possible for Demelza's team to come home with us last Christmas Eve – and they allow Lottie to continue to give the care our little girl still needs.

We really don't know if Darcey will be with us for Christmas this year. We dare not look any further ahead than a few days at a time. Whatever happens now and in the future, we will need Demelza's ongoing support. But sadly, we are not unique. I do know, with absolute certainty, that there will be other children just like Darcey and their families who will need them this Christmas to make their festive wishes come true.

Thank you so much. From me, Darren, Archie and especially Darcey, have a wonderful Christmas.

Zoe

Zoe

Darcey's mummy



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www.demelza.org.uk/christmas