



Registered Charity No. 1089657



*Grace*

A little girl whose smile says a thousand words, whose laugh is infectious and whose story simply inspires

# *Amazing Grace*

**Grace's birth gave us immediate joy as we became a family of three and first time parents. We had no warning that our baby girl was going to be so different from the daughter we dreamed about. We soon discovered how much our lives were about to change....**

On leaving hospital we found ourselves bouncing between many different hospitals and specialists. Grace was admitted four months later and diagnosed with a rare genetic condition called CFC Syndrome which typically affects the heart (cardio) facial features (facio) and skin (cutaneous). This genetic mutation causes severe cognitive delay and problems with motor skills and means Grace cannot stand or walk and does not know how to communicate. She is also really sensitive on her arms and hands and cannot hold or touch anything for very long.

During this time, we also discovered there was a needed work move to take us overseas. So, in the first six months of parenthood, we had to come to terms with our beautiful baby girl with needs we could not even begin to imagine as well as saying goodbye to the life and home we had built over the last ten years.

**Fast forward to the three years we have been in the UK.  
Grace is not only our precious gem but also our shining star!**

Grace started at the Dame Vera Lynn Trust School for Parents in December 2012 and could not sit unsupported, refused to touch anything and could not tolerate loud noises of any kind. Today, she is sitting on her own, spinning around and reaching to carefully explore the world around her. This is all due to the amazing work of the dedicated team at School for Parents. They have not only taught Grace how to accomplish these wonderful milestones but also taught us the most important lesson of all – how to play with our daughter!

We cannot begin to tell you how difficult it is when all you want to do is hold your daughter's hand and enjoy those precious early years together and you just don't know how to do it.

We are so grateful to the Dame Vera Lynn Trust for teaching us how to be the family we want to be and have been our saving grace in raising such a beautiful and extraordinary little girl.

*C J Mortimer*



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