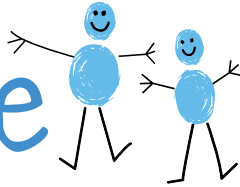
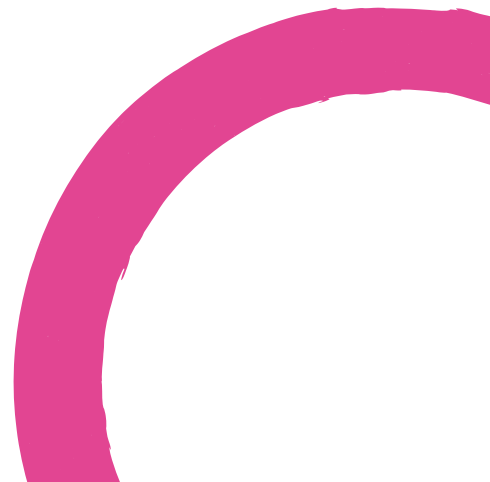


The True   
Colours Trust



# BREATHING SPACES

IMPROVING THE EXPERIENCES OF PARENTS  
AND CARERS OF CHILDREN IN HOSPITAL





Bristol Royal  
Hospital for  
Children

**The Breathing Spaces Fund for parent and carer rooms in hospitals was established by the True Colours Trust in 2018, inspired by Lisa and Mike Spinks' experiences with their son Rory.**

### **Lisa and Mike Spinks' Story**

Our son Rory was diagnosed with athymic complete DiGeorge syndrome in October 2013, which essentially means that he was born without a functioning immune system. As a result, we spent the best part of 3 years in and out of hospital, which included many long and difficult stays. Having a seriously ill child in hospital is one of the most stressful experiences a parent can go through and all of us respond in different ways to the pressures of hospital life but most of us, at some point feel lonely, frightened and far away from home and the support of our friends and family.

We spent the majority of our time with Rory in his room day and night, which involved complicated rotas to ensure he was never left, that we both saw our other sons and that Mike could continue to work full time. Sometimes, we just needed a break: when Rory went to the operating theatre, we didn't want to wait by an empty bed but we were too nervous to leave the hospital; we had to have many difficult conversations with the medical staff and afterwards we needed to talk (or cry) and not in front of Rory; Rory was on TPN for the majority of his life which meant he was fed intravenously and as a result we never felt that comfortable eating in front of him; or sometimes we just wanted to connect with someone else who knew what we were going through – other parents.

Unfortunately, sitting rooms/kitchens for parents or carers in hospitals are often given very little thought – it is the child who is sick after all. This is true of course, but we as parents play a vital role in our child's care team so this needs to be seriously re-evaluated. If we look after the parents, then they are better fuelled physically and emotionally to look after their child so everyone benefits.

Mike and I are determined to do what we can to make families' experiences in hospital more bearable, to help parents develop friendships, share their experiences and give them the space they deserve. **Lisa and Mike**

**If we look after the parents, then they are better fuelled physically and emotionally to look after their child so everyone benefits.**

Lisa Spinks, Parent



*It takes me away from the clinical side of the hospital for a while and feels more like being at home.*

Parent, Glasgow



Bristol Royal Hospital for Children



## The Need

Parents and carers of seriously ill children can spend significant periods of time in hospital with their child. They are often far from home, unable to spend time with family members, their other children and their normal support networks. They may face financial difficulties – for many, it can be difficult to work. They may also be faced with having to buy costly meals in cafes and restaurants, unable to get to a kitchen to prepare their own meals.

Well designed and well-equipped parent/carer rooms can significantly improve long stays in hospital for a child's family, providing parents and carers with somewhere to step away from their child's bedside, make a cup of tea, speak with other parents, call family or friends or just take some time for quiet reflection and respite.

A study undertaken by researchers in the UK and Australia in 2019, found that when asked what would have improved their experience in the PICU "parents recommended the provision of a parents' respite room that included snacks, toiletries, facilities for showering or washing clothes, and phone charging access."<sup>1</sup>

## About the Breathing Spaces Fund

Over the last five years, the True Colours Trust has funded 18 Children's Hospitals across the UK to create or refurbish parent/carer rooms, known as Breathing Spaces. Through our work, we have demonstrated the need for these rooms and learned about the impact these rooms can have on parents and families. Our hope is that many other hospitals will be inspired to create Breathing Spaces on their wards, improving the experiences of parents and carers of children in hospital.

We are often asked for more information on the programme and the learning we have gained from supporting the development of rooms across the country.

We have produced a user-friendly information pack and short film, both of which can be accessed via our website at [www.truecolourstrust.org.uk](http://www.truecolourstrust.org.uk)

We would also be delighted to speak with you if you would like more information about the process of developing such a room or the impact that they can have. Please contact Catherine at [info@truecolourstrust.org.uk](mailto:info@truecolourstrust.org.uk).

1. Butler A, Copnell B, Hall H (2019) When a child dies in PICU: Practice recommendations from a qualitative study of bereaved parents.